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ABSTRACT

This curriculum is designed to enable youth and young adults with disabilities to gain greater personal control over their lives by providing them and their families with information and skills that support the exercise of self-determination. The youth/young adult family member with a disability is a full participant in all activities. The curriculum is composed of 15 modules: "What Is Self-Determination?" "Creating a Personal Futures Plan," "Conducting Family Meetings," "Identifying Values and Goals," "Recognizing Opportunities for Choice-Making," "Supporting Informed Choice-Making," "Persevering in Choice-Making," "Realizing Your Vision," "Solving Problems," "Resolving Conflicts," "Advocating for Yourself," "Connecting with Community Resources," "Participating in Political Systems," and "Continuing the Journey." Each of the 15 modules includes goals, objectives, activities, instructional procedures, and questions for review and reflection. The curriculum includes a parent and a youth questionnaire on self-determination; forms for creating maps of the individual's background, relationships, places, preferences, choices, and future vision; role play scenarios; and a family networking form. (Some modules contain references.) (JDD)

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UNIVERSITY OF MINNESOTA

Self-Determination for Youth with Disabilities

A Family Education Curriculum

EC 303708

Institute on Community Integration (UAP) • College of Education • University of Minnesota

Developed by Brian Abery, Ann Eggebeen, Liz Rudrud, Katrina Arndt, Louise Tetu, Jim Barosko, Anne Hinga, Marijo McBride, Patrice Greger, and Krista Peterson

The College of Education

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First, we would like to thank the students with disabilities and families who stimulated us to think about self-determination in a new way, and gave us the benefit of their experience as we designed this curriculum.

We would also like to acknowledge the invaluable input we received from our project advisory committee, who helped us stay on track.

And, we would like to thank the members of the self-advocacy organizations Advocating Change Together and People First of Minnesota. As adults with disabilities who have passed through the years addressed in this curriculum, they shared with us a wealth of insight into the needs and possibilities related to self-determination for youth/young adults with disabilities.

Overview: *Family Education Curriculum*

Self-determination: what does it mean, and what does it have to do with young people who have disabilities and their families? Self-determination can be defined as *the intrinsic drive to exercise control over one's thoughts, feelings, and behaviors*. The potential to be self-determined exists in all individuals, regardless of severity or type of disability. For that potential to be developed and effectively expressed by young people with disabilities, they must acquire specific skills, knowledge, and attitudes. They also must have opportunities to practice those skills, use that knowledge, and express those attitudes. The purpose of *Self-Determination for Youth with Disabilities: A Family Education Curriculum* is to enable youth and young adults with disabilities to gain greater personal control over their lives by providing their families with information and skills that support the exercise of self-determination.

Sometimes an emphasis on family roles and responsibilities has been interpreted as excluding individuals with disabilities. Often the term "family" as used by services and organizations has grown to mean parents or others deciding what is best for the person with a disability and making decisions for them, even when they reach adulthood. In this curriculum, the youth/young adult family member with a disability is a full participant in all activities, and the terms "family" and "family members" as used here include everyone.

Curriculum Content

Self-Determination for Youth with Disabilities: A Family Education Curriculum is composed of 15 modules, each of which covers an important aspect of self-determination by youth and young adults with disabilities:

- **Module 1: What is Self-Determination?** This module is designed to guide the family in creating a working definition of self-determination. The definition will be the foundation of their focus on enhancing the exercise of self-determination by the youth/young adult with a disability.
- **Module 2: Creating a Personal Futures Plan**. The purpose of this module is to provide a process through which the young person with a disability (the focus person), working with other family members and significant others, can develop a vision and goals for his/her life based on the individual's capacities, values, and interests. As part of the discussion activities, the focus person and other participants describe the focus person's background and history, relationships, places he/she goes in the community and method of

The purpose of this curriculum is to enable youth and young adults with disabilities to gain greater personal control over their lives by providing their families with information and skills that support the exercise of self-determination.

transportation, the choices he/she makes, preferences, and long- and short-term goals.

- **Module 3: Conducting Family Meetings**. The purpose of the family meetings module is to help the family members identify successful strategies for communicating with each other, making decisions, and discussing issues as a family unit. As part of the module, they are asked to identify how they currently conduct family meetings, evaluate what works and doesn't work in their meetings, and practice new meeting strategies.
- **Module 4: Identifying Values and Goals**. This module is designed to help the family identify what is important to their family as a group and to individual family members. The discussion activities are designed to enhance participants' understanding of the history of their family and individual values, and how these values impact their lives and goals.
- **Module 5: Recognizing Opportunities for Choice-Making**. The purpose of this choice-making module is to help family members identify how they make choices and how they might improve their choice-making skills. In addition, the module helps participants identify realistic opportunities for the focus person to use his/her choice-making skills and thereby take risks and build the self-confidence he/she will need when facing challenges in the future.
- **Module 6: Expanding Opportunities for Choice-Making.** In this module, participants identify ways to expand current opportunities for choice and self-determination within the family. Activities include creation of choice maps documenting different types of choices each member makes, and discussion of ways to support increased choice-making by the member with a disability.
- **Module 7: Supporting Informed Choice-Making.** This module is designed to help families practice the skills for informed choice-making. These skills include supporting other family members, gathering useful information, and generating alternatives.
- **Module 8: Persevering in Choice-Making.** The purpose of this module is to help family members support each other in practicing choice-making, and persevering when choices don't work out.
- **Module 9: Realizing Your Vision**. The purpose of *Realizing Your Vision* is to help participants identify the long- and short-term goals and plans for the future of the focus person, as well as the behaviors, actions or steps necessary to reach those goals.
- **Module 10: Solving Problems**. This module examines the importance of problem-solving and explores the family members' personal and group problem-solving styles. The module reviews a series of effective steps to problem-solving, and discusses how participants can support each other when solving problems.

In this curriculum, the youth/young adult family member with a disability is a full participant in all activities, and the terms "family" and "family members" as used here include everyone.

- **Module 11: Resolving Conflicts.** The *Resolving Conflicts* module focuses on identifying current methods family members use to resolve conflicts, and developing skills in successful negotiation.
- **Module 12: Advocating for Yourself.** The purpose of the personal advocacy module is to assist family members in defining what personal advocacy means for them, and identifying how participants can support each other in advocating for themselves in the family and the community.
- **Module 13: Connecting with Community Resources.** This module guides the family to a broader perspective on the resources in their community and how to effectively access them to support self-determination. In addition, the module can help the participants gain a broader understanding of how specific systems impact their family and individual lives, and how to effectively work within the systems to access resources, supports, and services when the need arises.
- **Module 14: Participating in Political Systems**. In this module, the family gains a broader understanding of how political systems can support self-determination and develops strategies for working with those systems to support the self-determination of family members.
- **Module 15: Continuing the Journey**. This module concludes the curriculum by reviewing key concepts, skills, and strategies and linking them in an overview of their role in ongoing support for self-determination by youth/young adults with disabilities.

Each of the 15 modules includes activities designed to promote in-depth discussion of topic areas. The modules vary in length, requiring one to two sessions to complete. Sessions generally last from one to two hours.

Curriculum Flexibility

The role of facilitators is to guide the participants through the activities, leading discussions and asking questions, modifying activities to meet the unique needs of the family, preparing materials, and charting the discussion.

Every family has its own strengths, capacities, values, communication style, and ways of doing things. For some families, the ideas put forth in *Self-Determination for Youth with Disabilities: A Family Education Curriculum* will be new concepts, requiring a good deal of reflection and discussion. These families who are "starting with the basics" may progress slowly through the curriculum, participating in discussions in all of the topic areas presented. For other families, the curriculum will provide a format to refine and/or enhance opportunities for self-determination that are already provided. These families may choose to participate in only a limited number of the modules. As a starting point, however, all families are encouraged to participate in the first three modules (*What is Self-Determination, Creating a Personal Futures Plan, Conducting Family Meetings*) because these modules lay the groundwork for the remainder of the curriculum. During the third module, *Conducting Family Meetings*, there is an activity that provides the opportunity for the family to decide which of the remaining modules they would like to complete.

Facilitator Responsibility

It is recommended that the curriculum be facilitated by two, rather than only one, individual. The role of facilitators is to guide the participants through the activities, leading discussions and asking questions, modifying activities to meet the unique needs of the family, preparing materials, and recording the participant responses. Many activities require facilitators to record responses by taking notes or documenting the discussion on a flipchart; this is more easily accomplished when one facilitator is responsible for note-taking and charting while the other focuses on the discussion.

To enable participants to select modules and activities that will meet their needs, facilitators must clearly and concisely present information regarding the goals, objectives, and content of each module to family members. The selection of modules and activities should be based upon the interests of the family, the needs of the youth/young adult with a disability, and the strengths/needs of the family with respect to supporting the self-determination of the member with a disability.

It is recommended that facilitators tentatively schedule the dates and times for each meeting at the initial session. There are activities in many of the modules that need a week or more for advance preparation by the facilitators and/or family. Tentatively scheduling the modules will help the facilitators plan ahead and leave adequate preparation time for those activities.

Throughout the activities and discussions the thoughts, comments, and preferences of all participants should be listened to and respected, especially those of the youth/young adult with a disability. An additional part of creating a climate in which the young person with a disability is respected is the use of people-first language during sessions. This means, for example, using the phrase "person with a disability" instead of "disabled person", "handicapped person", or "the disabled." People-first language emphasizes the person as an individual human being, rather than as a condition or category.

Though the primary purpose of these modules is to support the self-determination of youth and young adults with disabilities, this curriculum can also enhance an entire family's ability to support greater personal control for all its members.

Curriculum Outcomes

A family that has participated in the curriculum will gain a clearer understanding of what self-determination means to their member with a disability and the rest of the family. The training will enable family members to identify where and how they can provide opportunities for increased personal control for the youth/young adult with a disability. And though the primary focus of these modules is to support the self-determination of young persons with disabilities, this curriculum can also enhance an entire family's ability to support greater personal control for *all* its members.

1 What is Self-Determination?

Introduction

Self-determination refers to the intrinsic drive of humans to be the primary determiners of our thoughts, feelings, and behaviors. It generates the attitudes and abilities that lead us to take charge of our lives, to make choices, and to set goals based on our needs, interests, and values. All of us, regardless of the severity or type of disability we have, possess the drive to be self-determined and need the opportunities and skills to act on it.

While many people learn self-determination skills informally, persons with disabilities may need specific instruction on ways to make decisions, solve problems, or advocate on their own behalf. For example, most of us learn to make choices because (1) we have the skills to identify our options and evaluate them before making our choice, (2) we know what choices are appropriate and realistic, (3) we are rewarded when we make a good personal choice, and (4) we have opportunities to make choices. Few persons with disabilities learn to make choices in this way. Persons with disabilities require direct instruction on how to (1) identify their choices and options, (2) evaluate options, (3) be motivated to make good choices, and (4) master these steps.

Families of youth/young adults with disabilities play a vital role in supporting the individual's self-determination. On a family level, through practices such as shared decision-making on issues affecting the entire family, the young person with a disability feels included and important as he/she plays a role in shaping the family's life. The young person learns to accept responsibilities that accompany shared decision-making and other practices, and also has the opportunity to develop his/her communication skills through learning to listen to others, respect others' views, and advocate for his/her own interests. These benefits are experienced not just by the member with a disability, but by all family members when the entire family practices and supports the exercise of self-determination.

When a family's self-determination skills are refined, other positive results are also likely:

- Family members become motivated to address personal concerns with the entire family, whether in family meetings or in an informal setting.
- Each family member experiences an increased sense of self-esteem and an increase in pride for the family unit that is able to constructively adapt to the concerns of its members.

Module Goals

- *The family will define self-determination and understand its application to their family.*

Module Objectives

- *The family will participate in a decision-making process to define self-determination.*
- *Through the decision-making process the family will familiarize themselves with the concept of self-determination and their initial reaction to the construct.*
- *The family will review others' definitions of self-determination as a basis for its own definition.*
- *Using its own definition of self-determination, the family will examine the role of self-determination in its members' well-being and steps the family can take to support it.*
- *The family will learn the benefits of enhancing the self-determination of its member with a disability.*

Module Activities

- *Creating Our Definition*
- *Why Self-Determination Matters*
- *Self-Determination in Our Family*

- The self-awareness of each individual is enhanced when the responsibility is placed on all members to address personal concerns with the entire family.
- This responsibility also promotes independence as each member thinks independently in order to form an opinion when voting on a family matter.
- Families who support development of self-determination in their members will likely notice an increase in each family members' positive social behaviors as a result of each family member sharing in the control of the family decision-making process.

Families who use the techniques taught in these modules will become skilled advocates for each other, advocates for the family as a whole, and personal advocates. Finally, the enhancement of family self-determination will lead family members to create a vision for their future, and together, realize that vision.

Overview of the Module

In this module, participants engage in several activities to help them define self-determination and think about how it applies to their family. Pre-session preparation for this module is necessary. Several weeks before the module meeting, send the family the questionnaires included in the Supplemental Information section at the end of this module; include a copy of the appropriate form for each family member (parent form, youth form). All family members are asked to fill these forms out individually, without comparing their answers with other family members. They will be instructed at that time to bring the completed forms to this meeting. The module is designed to be completed in one session of approximately two hours.

In this module, family members engage in several activities to help them define self-determination and think about how it applies to their family.

Activity Plans

Activity 1: Creating Our Definition

Introduction

It is often a good idea, when introducing a new concept, to have participants think about their personal definitions of that concept. This is the rationale behind the first activity in this module on self-determination. The participants take part in a decision-making process that asks them to define self-determination for themselves as individuals and as a family, then looks at common definitions of the construct, and, lastly, asks them to refine their personal and family definitions based on the added information.

Materials Needed

Flipchart, pens, paper, easel; the newsletter *IMPACT: Feature Issue on Self-Determination*, available from the Publications Office of the Institute on Community Integration, University of Minnesota, (612) 624-4512 (call for cost and ordering information).

Preparation for Facilitator

Two weeks prior to the session, distribute to participants the *What is Self-Determination* questionnaires (see pages 12-15 at the end of this module). Also, order for participants copies of *IMPACT: Feature Issue on Self-Determination* (see Materials Needed). Read through these materials before the session.

Preparation for Family

The family members should each have their completed *What is Self-Determination* questionnaires with them.

Instructional Procedure

- Introduce the module and activity by explaining to the family that the purpose is to get a clear idea of what self-determination is and how it relates to their family members.
- Ask family members to get out their completed questionnaires.
- Ask the family if one member would like to start by telling one thing they wrote down for "self-determination skills". Let each interested family member state one skill from their list. Write these responses on the flipchart under the heading "Skills".
- Using a new sheet on the flipchart, make similar lists for "Knowledge" and "Attitudes and Beliefs".

It is often a good idea, when introducing a new concept, to have the family members think about their personal definitions of that concept.

- Flip back to "Skills" page on the flipchart and ask family members to find any statements every member has listed. (If there is no consensus on statements, ask the family to identify the statements that were most commonly referred to.) Circle these. Do the same for "Knowledge" and "Attitudes and Beliefs".
- Return to the skills page once more and ask the family to look at the different responses and try to explain why the differences occurred.
- Using the flipchart results, write a family definition of self-determination. Placing all three pieces of paper on the wall or floor in front of the family, make one skill sentence all can agree to. Then create one sentence for knowledge, and another for attitudes and beliefs.
- Hand out the *IMPACT* issue on self-determination and refer to the articles, *Getting Beyond 'Yes': Holly's Story* and *From Assembly Line to Activism: Gloria's Story.* Point out specific definitions of self-determination in these articles and read them aloud. What are the participants' reactions to these individuals' definitions of self-determination? In what ways are these definitions similar to and different from those of the family members?
- Ask family members to look back at the family definitions of self-determination. Do they wish to make any changes in it in light of the additional information they've received?
- Ask family members to review their personal definitions of self-determination written on the bottom of their questionnaires. If any wish to revise them, ask them to rewrite the definitions on the back of the same paper. After they've done this, ask for volunteers to read both versions and describe why they made the changes.

Review and Reflect

- Did changes in definitions result in greater agreement or disagreement on the definition?
- Did the family include those statements that they all agreed upon in their final definition of self-determination?
- Does everyone accept this definition of self-determination?
- If everyone does not accept this definition, how do we further refine the definition?

Module activities should be adapted to allow the fullest possible participation by the youth/young adult with a disability.

Activity 2: Why Self-Determination Matters

Introduction

Once the family has compared its definition of self-determination with various other definitions, it is important that they understand why it is important to enhance the self-determination of the youth/young adult with a disability, other family members, and the family as a unit. This activity sets the stage for the remainder of the module by establishing the relevance of self-determination for the well-being of the entire family.

Materials Needed

The brochure, *Why Families Support Self-Determination*, available from the Publications Office, Institute on Community Integration, University of Minnesota, Minneapolis (call for cost and ordering information: (612) 624-4512). Flipchart, pens, paper, easel; Skills, Knowledge, and Attitudes sheets from Activity 1.

Preparation for Facilitator

Acquire copies of the brochure for each participant.

Preparation for Family

None.

Instructional Procedure

- Begin the discussion by asking, "Why do you think self-determination as your family has defined it is important?" If the family struggles to respond, refer back to their Skills, Knowledge, or Attitudes pages and ask, "Why do you think this skill is important?" "Why do you think this knowledge is important?", etc. Make a list of their responses on a new sheet of paper.
- Hand out the brochure *Why Families Support Self-Determination* and spend several minutes summarizing aloud each rationale for self-determination listed. Answer questions as they arise.
- Ask if family members agree or disagree with any aspects of the rationales in the handout. Ask them to describe why they agree or disagree.

Before learning skills to support self-determination, a family may need to become convinced that self-determination is important for the well-being of its members.

Activity 3: Self-Determination in Our Family

Introduction

Now that the family recognizes what self-determination is and why it is important for the family member with a disability and for the other family members, the family must take steps to actually support and encourage the exercise of self-determination by all family members.

Materials Needed

The videotape, *It's Never Too Early, It's Never Too Late* (available from the Minnesota Governor's Planning Council on Developmental Disabilities, (612) 296-4018; call for cost and ordering information); VCR and monitor.

Preparation for Facilitator

Preview the videotape.

Preparation for Family

None.

Instructional Procedure

- Ask the parents and other adult family members to think of a place outside the home where they feel self-determined. Ask them to describe the place or situation and answer the following questions:

  1) What is it about that specific situation that makes you feel self-determined?

  2) What do you *do* in that situation that makes you feel self-determined?

  3) What do you *think* in that situation that makes you feel self-determined?

- Ask all family members to think of a situation in the home in which they feel self-determined. Ask them to describe the situation and answer the following questions:

  1) What about that situation makes you feel self-determined?

  2) What do you do in that situation that makes you feel self-determined?

  3) What do you think in that situation that makes you feel self-determined?

  4) How can you get that same feeling in other places at home?

- Ask all family members to discuss how they can set up the home so that the youth/young adult with a disability has more opportunities to feel self-determined.

- The family will next view the videotape, *It's Never Too Early, It's Never Too Late*, in preparation for the next module on personal futures planning. Prepare the family for the videotape by defining personal futures planning: a person-centered, planning process that can be used for anyone. Let them know that the videotape shows

It's not enough to know about self-determination. The family must take steps to actually support and encourage the exercise of self-determination by all family members.

actual Personal Futures Plans for adults with moderate to severe developmental disabilities that have lived in restrictive settings. It gives real world examples of the process and outcomes of personal futures meetings. At the next session the family will actually develop a Personal Futures Plan with the young person with a disability.

Preparation for Next Module

In the next module, the youth/young adult with a disability, in collaboration with other participants, will develop a Personal Futures Plan. In preparation for that session, ask the young person and his/her family to think about extended family members, friends, or others who are significant people in the young person's life and who would have valuable input in development of the plan. The plan will be focused on the person's capabilities, interests and needs, and based on the memories and perceptions of the participants. The family should invite these people to attend the next session with them.

Supplemental Information

See following pages for the *What is Self-Determination?* questionnaires to be completed by participants during this module.

Defining self-determination and exploring how it applies to the family has set the stage for Module 2, which focuses on a self-determination plan for the youth/ young adult with a disability.

Self-Determination for Youth with Disabilities:
A Family Education Curriculum
What is Self-Determination?
Parent Questionnaire

Your Name: ______________________________

Please fill out this questionnaire as preparation for the Family Support and Education's introductory module on self-determination. Encourage all family members to fill out their copies (Note: Parents and youth have different forms). As much as possible, each family member should complete his/her own questionnaire without assistance from others.

As you answer the following questions please refer to this definition of self-determination as it applies to your son(s) or daughter(s) : "*Self-determination is making choices that allow you to control your life to the maximum extent possible based on pursuit of your needs, interests and values.*" Please note that the definition refers to an amount of control appropriate to the age of your child(ren).

I. Skills Necessary for Self-Determination

Please list up to four of the most important *skills* that children and youth need to be self-determined.

Example: To be self-determined, children and youth need to. . .
1. Make decisions according to their personal values.

To be self-determined, children and youth need to:

1.

2.

3.

4.

(Others)

II. Information Children Need to know to be Self-Determined:

Please list what you think are the four most important things that children and youth need to *know* so that they can successfully display self-determination.

Example: To successfully display self-determination, children and youth need to know about. . .
1. Laws and policies that protect their rights.

To successfully display self-determination, children and youth need to know about:

1.

2.

3.

4.

III. Attitudes and Beliefs Leading to Self-Determination:

Please list what you think are the four most important *attitudes or beliefs* that children and youth need to experience self-determination.

Example: Self-determined children and youth think or feel...
1. That they are good persons.

Self-determined children and youth think or feel. . .

1.

2.

3.

4.

IV. What does self-determination mean to you?

Self-Determination for Youth with Disabilities:
A Family Education Curriculum
What is Self-Determination?
Youth Questionnaire

Your Name: ____

Please answer the following questions without the help of other family members, and without comparing their answers to your own. As you answer the following questions please use this definition of self-determination: "*Self-determination* means being in control of your life, being able to make good choices, and taking steps to reach your personal goals and dreams." Think of self-determination as being "in charge" or "in control" of your life. When you answer the questions below try to think about things that allow you to take charge of your life, at school, at home, and when you're out with friends.

I. Skills of People Who Are Self-Determined

Please list what you think are the four most important *skills* that people your age need so they can be in control of their lives.

Example: To be self-determined, a person needs to be able to. . .
1. Ask for help when they have a problem.

To be self-determined, a person needs to be able to:

1.

2.

3.

4.

(Others)

II. Things People Need to Know About When They Are Self-Determined

Please list what you think are the four most important things a person needs to *know* so they can be in control of their lives, and meet their personal goals.

Example: To be self-determined, a person needs to know about. . .
  1. Laws and policies that protect their right to make their own choices.

To be self-determined, a person needs to learn or know about:

1.

2.

3.

4.

III. Attitudes and Beliefs People Need to be Self-Determined

Please list what you think are the four most important *attitudes or beliefs* that people your age need to be in control of their life.

Example: A person who is self-determined is someone who thinks/feels. . .
  1. That they are a good person.

A person who is self-determined is someone who thinks/feels:

1.

2.

3.

4.

IV. What Does Self-Determination Mean to You?

2 Creating a Personal Futures Plan

Introduction

Personal futures planning is a strategy that is becoming widely used to assist persons with and without disabilities in setting personal goals and establishing a vision of the future. Futures planning is more than just a plan, it is an ongoing problem-solving process. It comes about through a small group of people who agree to meet for mutual support, brainstorming, and strategizing. This "circle of support" or "person-centered team" makes commitments and takes action to ensure that changes are accomplished for the focus person.

The purpose of a personal futures planning session is to provide a process through which a young person with a disability (the *focus person*), their family, and their significant others can ask questions and identify the individual's capacities, values, and interests. Personal futures planning is a style of planning based on the assumption that there are no simple answers to complex problems. It is a process of asking questions and learning to produce actions or directions to try. Ultimately this process will create a future vision for the focus person based on his/her strengths, interests, and abilities.

Personal futures planning is a process that can be used by people of all ages and levels of ability. The first purpose of the process is to develop a profile of the focus person. This profile covers several areas of the individual's life including history and background, relationships, places in the community/transportation, choices, preferences, and focus on the future for self-determination.

The Personal Futures Plan developed will be useful throughout *Self-Determination for Youth with Disabilities: A Family Education Curriculum* to provide direction and ideas for enhanced self-determination. As a family participates in the curriculum, the personal futures planning document can be referred back to and used as guide for enhancing the focus person's self-determination. The information from the Personal Futures Plan, for example, may provide the family and significant others with ideas for expanding choice-making opportunities for the focus person who wants to improve choice-making skills.

Overview of the Module

During the personal futures planning process, the youth/young adult with a disability (focus person) works with the other participants to develop a vision for his/her future. The memories, thoughts, and ideas of the focus person, his/her family, and significant others

Module Goals

- *The focus person, along with his/her family and significant others, will develop a vision and goals for the focus person's future.*

Module Objectives

- *The vision and goals will be based on the strengths, interests, and capabilities of the focus person, and will be developed from the memories, thoughts, and ideas of the focus person, his/her family, and significant others rather than from records or assessments.*

Module Activities

- *Creating a Personal Futures Plan*

will be collected and a personal profile and vision of the future will be developed from this information.

While facilitators will have to determine which division of labor works best for them based on their experience, the suggested method of facilitation is for one facilitator to lead the discussion and the other to record the information on the flipchart. The information on the flipchart is in the form of "maps" that illustrate the pattern of a person's life. Visual representations - drawings of people, places, and things; arrows indicating relationships or direction of movement; and use of colors - can make the maps more interesting and understandable. Using graphic symbols in this way helps to stimulate creativity and to encourage participation by people who have difficulty with words. This module is designed to be completed in one session of approximately two hours.

During the personal futures planning process, the youth/young adult with a disability (focus person) works with the other participants to develop a vision for his/her future.

Activity Plans

Activity 1: Creating a Personal Futures Plan

Introduction

The goal of the Personal Futures Plan is to assist the focus person in taking some degree of control over his/her life. The process describes a future based on strengths, interests, and capabilities. It does not look at available services, but considers what the person needs to participate in the community.

Materials Needed

Large flipchart, tape or flipchart stand, multi-colored markers, sample maps (for facilitator reference) from the Supplemental Information section (pages 27-38) at the end of this module.

Preparation for Facilitator

Preview the personal futures planning module, including the sample maps in the Supplemental Information section at the end of the module. In addition, read through *Assumptions for Personal Futures Planning* (see page 26 in the Supplemental Information section) and, if desired, the booklet, *It's Never Too Early, It's Never Too Late* (available from the Minnesota Governor's Planning Council on Developmental Disabilities, (612) 296-4018). Plan ahead of time as to which facilitator will be documenting information on the flipchart, and which will guide the discussion. At the end of the last session, you should have asked the youth/young adult with a disability (focus person), and his/her family to identify and invite significant others (friends or others) who wish to be a part of the futures planning session.

Preparation for Family

Invite significant others of the young adult with a disability to participate in the planning session.

Instructional Procedure

- Provide participants with a brief introduction to the personal futures planning process (base your comments on the information in the Introduction section of this module on page 18). You may want to compare personal futures planning to a treasure hunt; the goal is to collect information about the focus person in the form of memories, thoughts, and ideas. Tell participants that today they will discuss six topic areas in the focus person's life: background, relationships, places, choices, preferences and the future.

The goal of the Personal Futures Plan is to assist the focus person in taking some degree of control over his/her life.

- Proceed through the six areas (Activities 1a-1f), using the suggested questions to prompt discussion. Ideally, one facilitator will lead the discussion while the other draws the maps on the flipchart. Give the focus person the opportunity to respond first to each question, then encourage the rest to add their ideas.
- After the session, transfer the information from the flipchart maps to photocopies of the maps from the Supplemental Information section of this module (pages 27-38). Send copies to the participants before the next session.

Activity 1a: Background Map

Introduction

In this first step of the personal futures planning session, the participants discuss the focus person's history. The purpose of this session is to document any event or memory that the participants feel are important for understanding the focus person's background. Specific dates or names are not important in piecing together a description of the person's past, but rather memories, events, and feelings that participants wish to share.

Instructional Procedure

- Introduce this activity by telling the family that the purpose is to get a picture of the background of the focus person, using memories, events, and feelings to create a map of the individual's personal history.
- While one facilitator is assisting in the discussion, the other facilitator can be documenting the information by drawing the background map on the flipchart. A sample map is found on page 27 in the Supplemental Information section at the end of this module. On the reverse side of the sample, is a blank map; after the session, the information from the flipchart should be transferred to a photocopy of the map, and then copied and mailed to participants. As you'll notice in the sample, the information can be depicted with pictures, symbols, arrows, words, and/or colors - any way that communicates the information clearly for the family.
- Ask the following questions to obtain information on background:

1) Where were you (the focus person) born?

2) How did you (the focus person) behave as a baby/child?

3) What were some major or memorable events that occurred in your (the focus person's) past?

4) What did you (the focus person) enjoy doing for fun or on vacations as a child?

Give the focus person the opportunity to respond first to each question, then encourage the rest of the participants to add their ideas.

5) What general memories do you have of your (the focus person's) childhood?

6) What schools did you (the focus person) attend?

7) What activities or subjects do you (the focus person) enjoy in school?

Activity 1b: Relationship Map

Introduction

In this second step of the personal futures planning session, participants discuss the focus person's relationships. The purpose of this section is to create a relationship or social network map that can help participants better understand the focus person's social relationships.

Instructional Procedure

- Introduce this activity by telling the family that they will next create a second map, focusing on the relationships of the youth/young adult with a disability.
- While one facilitator is assisting in the discussion, the other facilitator can be documenting the information on the relationship map on the flipchart. A sample map is found on page 29 in the Supplemental Information section at the end of this module. On the reverse side of the sample, is a blank map to be photocopied and completed following the session, and mailed to the participants.
- Using the relationship map, draw and/or list the names of family members, friends, and service providers. Generally, the names of people the focus person feels closest to or spends the most time with should be written toward the center of the circle.
- Ask the following questions to obtain information on relationships:

1) Who are the people with whom you (the focus person) spend the most time? (These people should be placed closest to the focus person in the center of the relationship circle.)

2) How much time do you (the focus person) spend with each?

3) Who are the people you (the focus person) feel closest to (if not the same as above)?

4) Who are the people with whom you (the focus person) has contact on a daily, weekly, monthly or yearly basis? (The more time spent with the focus person, the closer to the center of the relationship circle they are placed.)

5) Are these persons friends, family, or service providers? (They should be placed in the appropriate section of the circle.)

Refer to the sample maps at the end of this module as guides for drawing maps.

6) Are there any animals or pets involved in your (the focus person's) life?

Activity 1c: Places Map

Introduction

In this third step of the personal futures planning, participants discuss places to which the focus person goes in the community. Included in this discussion are how often the focus person goes out into the community, how he/she gets there, and with whom.

Instructional Procedure

- Explain to the family that they are now going to create a third map identifying places frequented by the focus person.
- While one facilitator is assisting in the discussion, the other facilitator can be documenting the information on the places map on the flipchart. A sample map is found on page 31 in the Supplemental Information section at the end of this module. On the reverse side of the sample, is a blank map to be photocopied and completed following the session, and mailed to participants.
- Using the places map, use symbols, names, and arrows to create a map of places the focus person goes into the community.
- Ask the following questions to obtain information about the places the focus person frequents or spends time at:

1) What places do you (the focus person) go to a lot in your neighborhood or community?

2) How do you (the focus person) decide whether to go to these places? How do you (the focus person) decide what to do when you're in these places?

3) What do you (the focus person) do in these settings?

4) Do you (the focus person) go to these places alone, in small groups, or in large groups?

5) How do you (the focus person) get to these places (what are the transportation options and needs)?

6) Where do you (the focus person) go to school/work?

7) What kind of transportation do you (the focus person) use to get there?

8) Are there places in the community where you (the focus person) would be supported in exercising self-determination?

9) Are there places in the community where you (the focus person) would not be supported in exercising self-determination?

By drawing the maps you may be providing the focus person with a visual aid that will enable him/her to participate more easily in the discussion.

10) What do you (the focus person) do at home for fun?

11) What do you (the focus person) do at home for chores?

12) How do you (the focus person) make choices about what fun activities to do at home?

11) How do you (the focus person) make choices about what chores to do at home and how to do them?

Activity 1d: Preferences Map

Introduction

In this fourth section of the personal futures planning session, participants discuss the focus person's preferences, in other words, what works for the focus person and what doesn't work.

Instructional Procedure

- Introduce this activity by explaining that the participants will now look at the focus person's preferences for certain people, activities, settings, choices, and experiences.
- While one facilitator is assisting in the discussion, the other can document the information on the preference map on the flipchart. A sample map is found on page 33 in the Supplemental Information section at the end of this module. On the reverse side of the sample is a blank map to be photocopied, completed, and mailed to participants after the session.
- Ask the following questions to obtain information on the focus person's preferences:

1) What type of person do you (the focus person) find hard to get along with?

2) What type of person do you (the focus person) get along with easily?

3) Are there people you (the focus person) would like to spend less time with?

4) What are the activities that you (the focus person) most enjoy doing, activities that motivate and interest you (the focus person)?

5) What are the activities that are boring, frustrating or undesirable for you (the focus person)?

6) What conditions, activities, and settings are most enjoyable for you (the focus person)?

7) What conditions, activities, and settings are most frustrating for you (the focus person)?

8) What choices do you (the focus person) dislike making?

This may be one of the first times the focus person has been asked in detail, "What do you like?", "What do you want?", and "What do you need?". Allow time for the person to think about and respond to the questions without others jumping in to answer.

9) What types of choices do you (the focus person) enjoy making?

10) In what ways can positive experiences be increased and negative experiences decreased?

Activity 1e: Choices Map

Introduction

In this fifth section of the personal futures planning session, participants discuss the choices made by the focus person independently and choices made by or with others. Many choices will fall into both categories; in other words, in some circumstances a choice is made independently and in other situations that choice is made by others or with the help of others.

Instructional Procedure

- Introduce this activity by explaining to the family that the fifth map they're going to make looks at choices the focus person makes alone and choices made with or by others.
- While one facilitator is assisting in the discussion, the other can document the information on the choices map on the flipchart. A sample map is found on page 35 in the Supplemental Information section at the end of this module. On the reverse side of the sample, is a blank map to be photocopied, completed from the flipchart map, and mailed to participants after the session.
- Ask the following questions to obtain information about choices:

1) What are the choices that you (the focus person) make on your own at home?

2) What are the choices that you (the focus person) make on your own in school?

3) What are the choices that you (the focus person) make on your own about being around other people your age?

4) What are the choices that you (the focus person) make together with parents about home, school, or being with others your age?

5) What are the choices that you (the focus person) make together with your teachers in school?

The aim of personal futures planning is to build on an individual's strengths, abilities, and interests. Focus on what the youth/young adult with a disability* can *do, not what he/she* can't *do.

Activity 1f: Future Map

Introduction

In this sixth and final section of the personal futures planning session, participants discuss dreams and goals for the focus person in relation to self-determination. Participants may want to use the information from the previous discussions to help formulate long- and short-term goals in self-determination and to identify the supports needed for the focus person to reach the goals.

Instructional Procedure

- While one facilitator is assisting in the discussion, the other facilitator can be documenting the information on the future map on the flipchart. A sample map is found on page 37 in the Supplemental Information section at the end of this module. On the reverse side of the sample is a blank map to be photocopied, completed, and mailed to participants after the session.
- Ask the following questions to obtain information on the focus person's future self-determination goal(s):

  1) What will your (the focus person's) life be like in the future in the area of self-determination?

  2) What are your (the focus person's) short term goals for using self-determination?

  3) What are your (the focus person's) long-term goals for using self-determination?

  4) What support and assistance do you (the focus person) need from others to reach those goals?

  5) What opportunities are available in the community to help you (the focus person) reach your self-determination goals?

  6) (To the other participants): How do you feel about [the focus person] pursuing those goals?
- At the conclusion of the personal futures planning session, indicate to the participants that their discussion has provided valuable information about the focus person, and that copies of the maps will be made for the focus person and other participants to keep. The information and ideas that are documented on the personal futures maps will be referred back to throughout the curriculum.

Preparation for Next Module

When Module 2 is completed, distribute and explain to participants the handout, *Family Meetings*, (see pages 48-50 at end of Module 3) to be used in the next session. This handout will provide background for the family as, in the next session, they become familiar with and practice the skills necessary for effective family meetings.

In this module, the focus person has worked with others to develop a vision for his/her future. The maps created here will be used throughout the curriculum to support movement toward making that vision a reality.

Supplemental Information

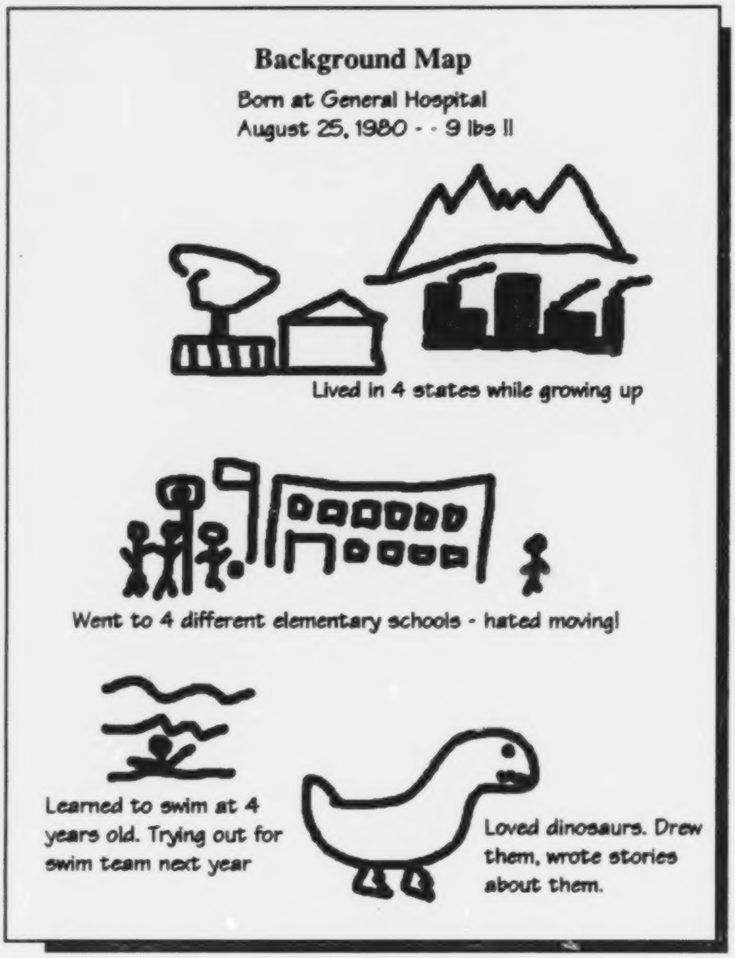
Assumptions of Personal Futures Planning

- Personal futures planning is an individualized, structured, possibility-based approach to life planning. A Personal Futures Plan represents a vision for a more desirable future. The plan is developed by a group of people who care about the individual and are willing to assist in making the plan a reality. *- Angela Novak Amado, Ph.D., Executive Director, Human Services Research and Development Center, St. Paul, Minnesota*
- The future is not designed by great events, but by the small things people do wherever they are. No contribution is too small.
- The aim of personal futures planning is to build on people's capacities and opportunities in networks and communities in order to allow desirable futures to be created and suggested.
- Personal futures planning is a process that can be used for all ages and levels of abilities.
- Personal futures planning is a style of planning based on the assumption that there are no simple answers to complex problems.
- Personal futures planning is a process of asking questions and learning to produce action or directions to try.
- Personal futures planning does not look at what services are available but rather considers things that need to happen so that an individual can fully participate in society.
- Personal futures planning identifies capacities and values, fosters collaborative learning and action, and encourages imagination and creativity.

From Mount, B. & Zwernik, K. (1989). *It's never too early, it's never too late: A booklet about personal futures planning*. St. Paul, MN: Reprinted by the Minnesota Governor's Planning Council on Developmental Disabilities.

Background Map: Sample

On this page is a sample of a completed sheet profiling the focus person's background and history as it relates to self-determination. On the following page is a blank background map; after the personal futures planning session, the information from the flipchart should be transferred to a photocopy of the blank map, and then copies mailed to participants.



Background Map

Born at General Hospital
August 25, 1980 - - 9 lbs !!

Lived in 4 states while growing up

Went to 4 different elementary schools - hated moving!

Learned to swim at 4 years old. Trying out for swim team next year

Loved dinosaurs. Drew them, wrote stories about them.

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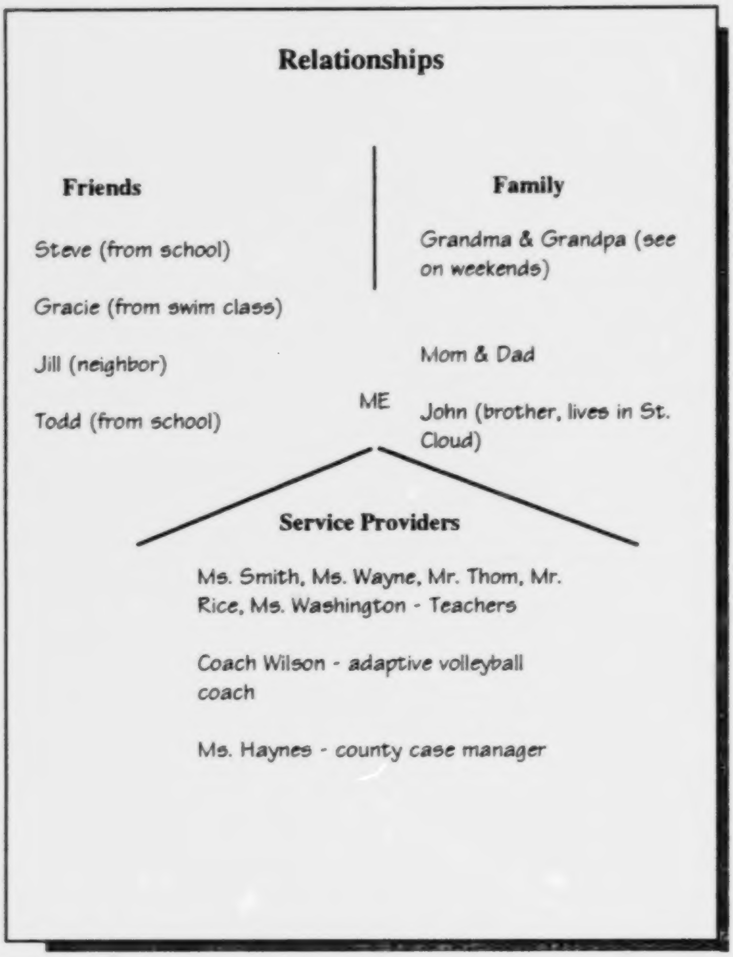
Background Map

Relationships Map: Sample

On this page is a sample of a completed sheet profiling the individual's relationships. On the following page is a blank relationships map; after the personal futures planning session, the information from the flipchart should be transferred to a photocopy of the blank map, and then copies mailed to participants.



Relationships

Friends

Steve (from school)

Gracie (from swim class)

Jill (neighbor)

Todd (from school)

Family

Grandma & Grandpa (see on weekends)

Mom & Dad

John (brother, lives in St. Cloud)

ME

Service Providers

Ms. Smith, Ms. Wayne, Mr. Thom, Mr. Rice, Ms. Washington - Teachers

Coach Wilson - adaptive volleyball coach

Ms. Haynes - county case manager

Relationships Map

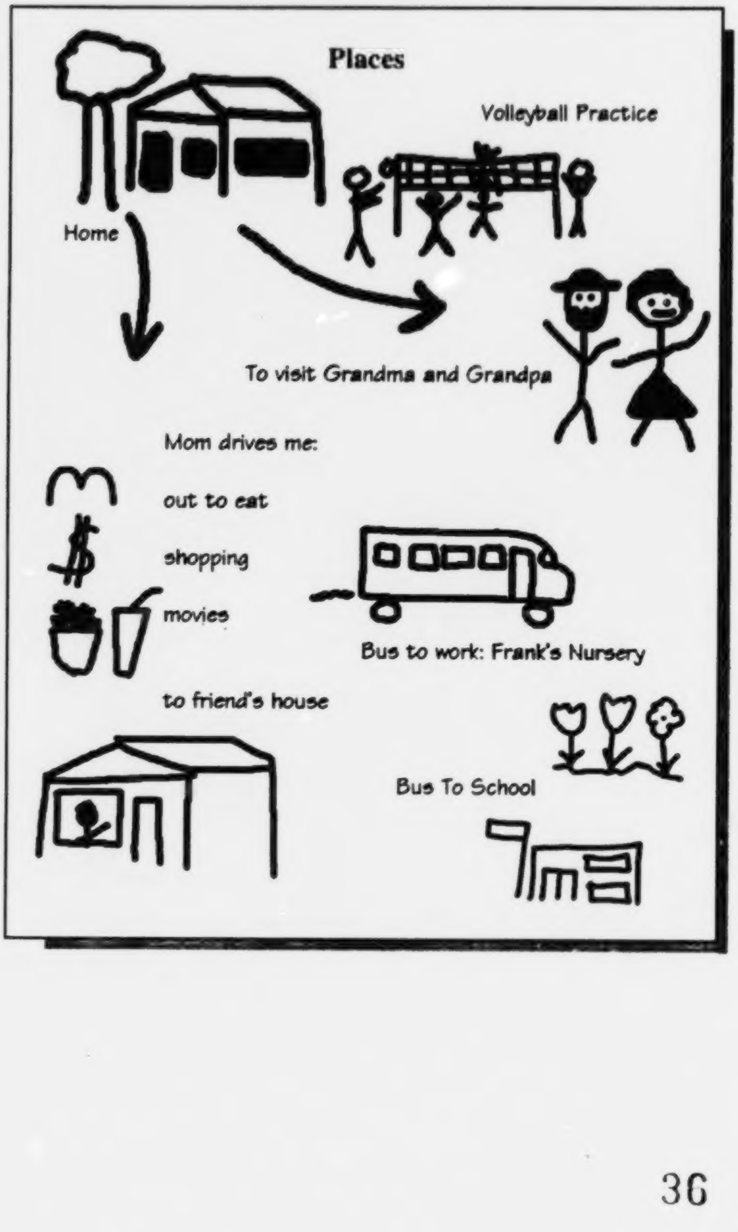
Friends

Family

Service Providers

Places Map: Sample

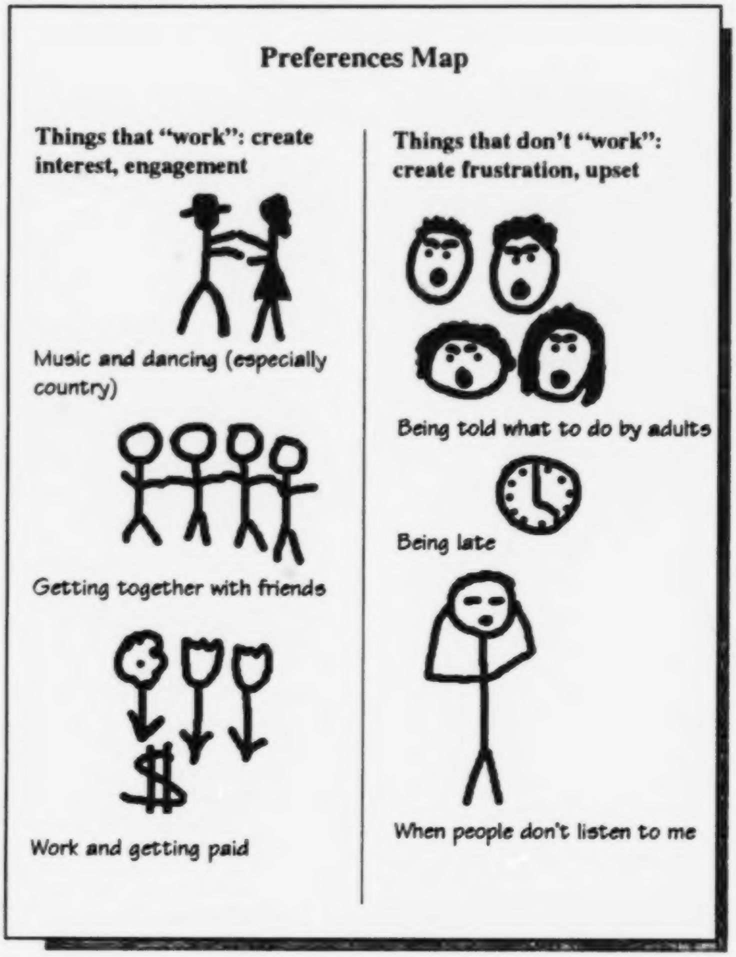
On this page is a sample of a completed sheet identifying the places the focus person frequents in the community. On the following page is a blank places map; after the personal futures planning session, the information from the flipchart should be transferred to a photocopy of the blank map, and then copies mailed to participants.


Places
Volleyball Practice
Home
To visit Grandma and Grandpa
Mom drives me:
out to eat
shopping
movies
to friend's house
Bus to work: Frank's Nursery
Bus To School

Places Map

Preferences Map: Sample

On this page is a sample of a completed sheet profiling the individual's preferences for all areas of their life. On the following page is a blank preferences map; after the personal futures planning session, the information from the flipchart should be transferred to a photocopy of the blank map, and then copies mailed to participants.



Preferences Map

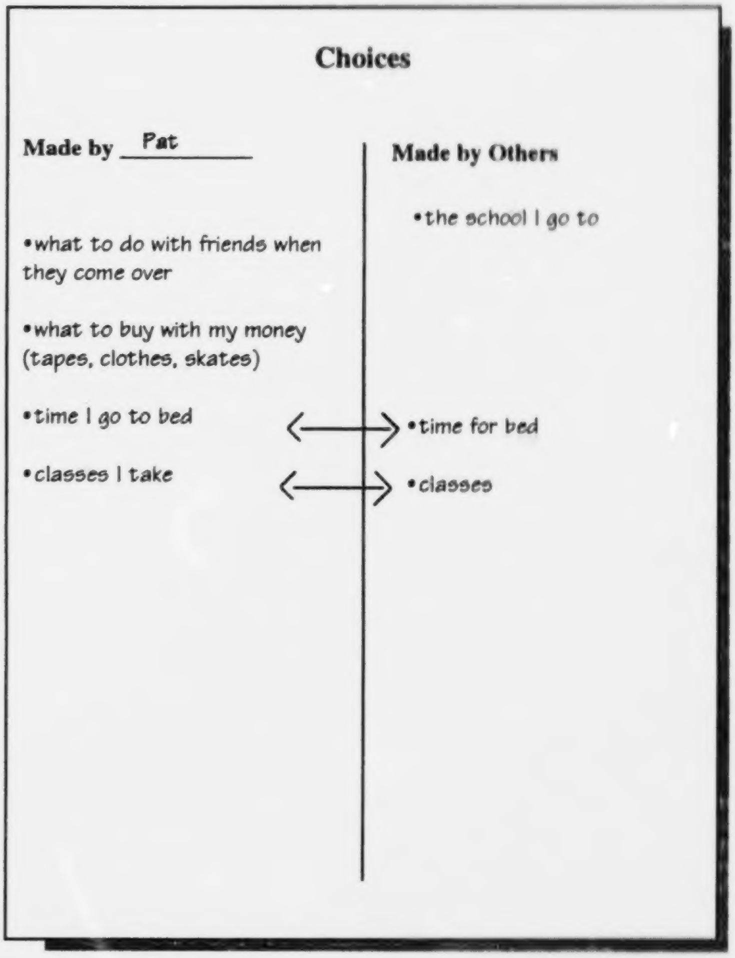
Things that "work": create interest, engagement	**Things that don't "work": create frustration, upset**
Music and dancing (especially country)	Being told what to do by adults
Getting together with friends	Being late
Work and getting paid	When people don't listen to me

Preferences Map

Things that "work": Create interest, engagement.	Things that don't "work": Create frustration, upset.

Choices Map: Sample

On this page is a sample of a completed sheet profiling the choices made independently by the focus person and choices made for them by others. Choices that are made collaboratively - both the focus person and others participating - should be written in both columns and a two-way arrow drawn between them. Also, choices that are sometimes made by the person and sometimes made by or with others, depending on the situation, should also be written in both columns and connected with an arrow. On the following page is a blank choices map; after the personal futures planning session, the information from the flipchart should be transferred to a photocopy of the blank map, and then copies mailed to participants.



Choices

Made by Pat		**Made by Others**
		•the school I go to
•what to do with friends when they come over		
•what to buy with my money (tapes, clothes, skates)		
•time I go to bed	⟷	•time for bed
•classes I take	⟷	•classes

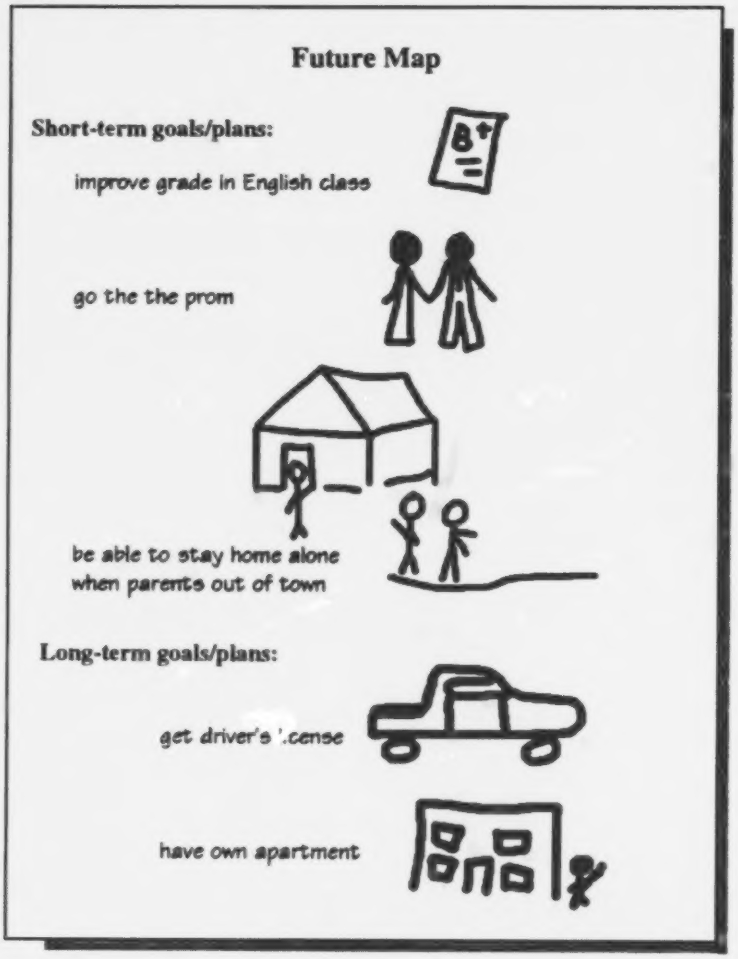
Choices Map

Made by ___________:

Made by Others:

Future Map: Sample

On this page is a sample of a completed sheet profiling dreams and goals for the focus person. On the following page is a blank future map; after the personal futures planning session, the information from the flipchart should be transferred to a photocopy of the blank map, and then copies mailed to participants.



Future Map

Short-term goals/plans:

improve grade in English class

go the the prom

be able to stay home alone
when parents out of town

Long-term goals/plans:

get driver's license

have own apartment

Future Map

Short-term goals/plans:

Long-term goals/plans:

3 Conducting Family Meetings

Introduction

Communication is a key to successful family functioning. Using techniques that enhance communication is therefore important to continued positive family interactions. The family meeting is one method used to improve and increase the honest discussion of issues concerning the family. Family meetings can also be a tool for supporting self-determination. During family meetings, youth/young adults with disabilities, along with other family members, can practice self-determination skills such as goal-setting, problem solving, advocating for a particular position, and negotiating. Through having opportunities to practice these skills in a safe, respectful environment, family members can gain the confidence to exercise the same skills in other settings, such as school, work, and in the community.

Overview of the Module

In this module, participants develop an understanding of family meetings as a strategy for dealing with family concerns in a manner that includes all family members in the discussion and decision-making. The family additionally will learn specific skills for conducting family meetings and will practice those skills through role-playing and through holding a mini-meeting during the session. During these activities the family will choose a designated facilitator or leader for their meetings. Everyone in the family should have a chance to be the facilitator, and as the family practices their family meeting technique, they will make note of strategies that are successful in conducting a productive meeting.

To insure that the implementation of this module is successful, it is important to remember that each family is unique and those unique qualities need to be respected. The family meeting is a vehicle to develop self-determination for family members, and opportunities for self-determination vary between families, within families, and across time. The module is intended to help the family start thinking about individual family members' levels of personal control, and how independence and interdependence are both components of self-determination. This module is designed to be completed in one session of approximately two hours.

Module Goals

- *The family will develop and enhance skills for conducting family meetings.*

Module Objectives

- *The family will develop an understanding of the purpose and strategies for holding family meetings.*
- *The family will demonstrate its ability to conduct an effective family meeting.*

Module Activities

- *Family Meeting Demonstration*
- *Defining the Role of Facilitator*
- *Selecting Modules*
- *Attending a Community Meeting*

Activity Plans

Activity 1: Family Meeting Demonstration

Introduction

Even if they don't hold formal family meetings, every family has a process by which they discuss issues and make decisions. The purpose of this activity is for the family to recognize the skills they already possess and use to make family decisions and resolve family issues. In this activity, the family will enact a typical family meeting. After demonstrating or practicing a family meeting, participants will discuss what they observed, how they felt, and how they can enhance their family meeting process. This information can be documented for further reference.

Materials Needed

Paper, flipchart, board to document observations; topic or agenda for the meeting; the handout *Family Meetings* (see pages 48-50 in the Supplemental Information section at the end of this module); camcorder, monitor, videotape.

Preparation for Facilitator

At the end of Module 2, copy and distribute the handout, *Family Meetings* (see pages 48-50 in the Supplemental Information section at the end of this module).

Preparation for Family

The family should receive and read the handout, *Family Meetings* (see pages 48-50 in the Supplemental Information section at the end of this module) prior to the session.

Instructional Procedure

- Introduce this module and activity by describing why family meetings are important and how they affect family members' self-determination (use the information in the Introduction to this module on page 39 as a basis for your remarks). Explain that the way a family makes decisions and resolves issues affects the level of self-determination family members exercise in the family. For that reason in this module they'll identify skills they already use to make family decisions and resolve issues, and will also identify new skills they would find helpful.
- Ask the family if they routinely hold family meetings. If yes, ask them to describe their process. If they do not hold meetings, ask how they discuss and reach decisions.

The purpose of this activity is for the family to recognize the skills they already possess and use to make family decisions and resolve family issues.

- Review the handout, *Family Meetings*, focusing on the sections on planning, structuring the discussion, and closing the meeting. Highlight the main points and ask the family if they have any questions regarding the material.
- Ask family members to develop a topic or agenda to be role played; this can be a real issue that the family is working on or a fabricated one, it is up to the family.
- Have the family role play a family meeting. Provide prompts and feedback during the role play if the family asks for it, or appears to be having trouble getting a meeting going. Also, take notes during the meeting, documenting how the family works together and how individual members participate in the meeting.
- If the role play was videotaped, review and critique the videotape.
- Discuss observations and ways to enhance skill development by asking the following questions:

  1) What was your impression of the family meeting?

  2) What did you observe?

  3) Was the agenda followed?

  4) How did family members interact?

  5) If conflict, tension, or disagreement arose, how was it handled?

  6) How were family members positively supported during the family meeting?

  7) What would you like to see changed?

  8) How did you feel the family meeting progressed?

  9) What strengths did you bring to the family meeting?

Review and Reflect

- How can you enhance the strengths you brought to the meeting?
- How can a means to enhance your strengths be monitored?
- What would you like to share that was not asked?
- How can family meetings enhance each family member's self-determination?

For many families, this will be the first time they've thought about holding structured family meetings. The activities should be adapted to support the family in developing a process that will work for them.

Activity 2: Defining the Role of Facilitator

Introduction

The purpose of this activity is for the family to enhance their skills with regard to a specific component of a family meeting: the role of a facilitator. The role of facilitator is dependent on the nature and format of the family meetings. Some families may be comfortable always using the same facilitator while others may want everyone to take turns facilitating. For some families, the facilitator role is the most important at the meeting, and for other families it is not that important. This activity gives the family a chance to talk about what they think a facilitator should do in meetings. It also gives the family a chance to assign any other roles they feel are necessary to conduct a successful family meeting. Facilitating a family meeting is one way to practice and refine the communication, listening and social skills that are important in self-determination.

Materials Needed

Paper, flipchart, markers to document the discussion; the handout *Family Meetings* (see pages 48-50 in the Supplemental Information section at the end of this module).

Preparation for Facilitator

At the end of Module 2, copy and distribute the handout *Family Meetings* (see pages 48-50 in the Supplemental Information section at the end of this module).

Preparation for Family

The family should have read the handout, *Family Meetings* (see pages 48-50 in the Supplemental Information section at the end of this module).

Instructional Procedure

- Introduce the activity by explaining to the family that the purpose of this activity is to identify ways in which they can structure their family meetings. Based on the section, *Facilitating the Meeting*, in the family meetings handout, have the family summarize what they understand to be a facilitator's role in a family meeting.
- Discuss and document the family's input with regard to who should facilitate family meetings, and what other roles are needed for successful meetings, by asking the following questions:

  1) Who should facilitate your family meetings? Should this be one person?

  2) Should this role rotate? Should there be a co-facilitator?

  3) How do you want your family meetings to run?

  4) Who should schedule the family meetings?

  5) Where should the family meetings be held?

  6) Should someone take notes? If yes, who?

Family meetings are one tool for creating a home environment that supports self-determination.

7) When should the family meetings be held?

8) Who should develop the agenda, or how should the agenda be developed?

9) What process needs to be put in place to review and monitor the effectiveness of the family meeting?

Review and Reflect

- How can learning how to facilitate a meeting lead to enhanced self-determination or personal control in a person's life?
- How do family members feel when they facilitate a meeting?

Activity 3: Selecting Modules

Introduction

The purpose of this activity is for the family to discuss and choose which of the remaining curriculum modules they would like to complete. This decision-making process can provide an excellent opportunity for family members to practice what they have just learned about conducting family meetings. It may also be helpful to use the personal futures planning document in this process and focus on the ways in which each module can contribute to helping the young person with disabilities reach the goals set in the personal futures planning module.

Materials Needed

Paper, flipchart, markers to document discussion; *Family Education Curriculum Modules List* (see pages 46-47 in the Supplemental Information at the end of this module); charts from the Personal Futures Plan.

Preparation for Facilitator

Copy an adequate number of *Family Education Curriculum Modules List* (see pages 46-47 in the Supplemental Information at the end of this module) for all participants, and bring the flipcharts from the personal futures planning module.

Preparation for Family

None.

At this point the family chooses which of the remaining curriculum modules they would like to complete.

Instructional Procedure

- Tell the family that there is one more activity in which they have a mini-meeting to make a decision about which of the remaining modules they wish to participate in. This will give them a chance to practice family meeting techniques, and also to exercise self-determination in relation to this curriculum.

- Ask family members to assign roles or organize themselves for the last meeting activity.
- Hand out copies of the *Family Education Curriculum Modules List* (see pages 46-47 at end of this module) to all family members. Display or have available the flipcharts from the personal futures planning module.
- Discuss with the family the remaining modules in which they would like to participate. Emphasize that module selection should be related to supporting the youth/young adult with a disability in achieving the goals in his/her Personal Futures Plan. Document family responses on the flipchart.
- In addition to asking in which modules they would like to participate, ask the following:

  1) Why would you like to participate in these modules?

  2) Are there modules that you feel are not appropriate or useful for your family?

  3) Why do you feel they are not appropriate or useful for your family?

Review and Reflect

- How do you feel the modules will enhance the young adult's self-determination?
- How do you feel the modules will strengthen the ability of the family to support the young person's self-determination?

Activity 4: Attending a Community Meeting

Introduction

The purpose of this activity is for the family to enhance their knowledge of the skills necessary to successfully conduct family meetings. To do this the family may find it helpful to attend one or more meetings of community organizations. This can give family members ideas about how other groups discuss issues and make decisions. After the community meeting the family will discuss their observations and the possibility of incorporating some of the strengths of the observed meeting into their own family meetings.

Families can learn new ways of decision-making and discussion from observing others, such as community meetings.

Materials Needed

Information on meetings within the family's community; paper and pen to document their observations.

Preparation for Facilitator

You may want to gather information on various meetings within the family's community, such as a community or neighborhood calendar of events from a local paper.

Preparation for Family

None.

Instructional Procedure

- Introduce this activity by explaining that the family will have an opportunity to attend a meeting in the community and observe some other ways for conducting meetings that they may want to apply to their family.
- Ask the family if there is a meeting of a club, civic or religious group, political body, school, or other organization that one or more family members would like to attend and observe. If so, write the information on the flipchart - date, time, location, group, who will attend. If steps need to be taken to gather information and/or to accommodate the attendance by the family member(s), list what needs to be done and how it will be accomplished.
- The family will discuss the outcome of the meeting activity at the start of the next module.

Review and Reflect

- How can the skills involved in facilitating and participating in family meetings be used in other areas of life to support self-determination?

Preparation for Next Module

- One or more family members may attend a community meeting and discuss the outcome during the next session.
- Ask the family to do two things in preparation for the next module: (1) Make a mental list of their personal, individual values - those principles or qualities that they believe are desirable, good, and important in life, and (2) locate family memorabilia such as photos, videos, slides, and letters to bring to the next session. They should try to locate memorabilia of people, places, or things that best reflect the current family values and how they were formed. The family members may want to hold a family meeting to collect and sort memorabilia and to list family values.

In this module, the family has focused on how it makes decisions and resolves issues. Having a respectful, inclusive process for discussion and choice-making will help the family support individual differences in values and goals, the topic of the next module.

Supplemental Information

Family Education Curriculum Modules List

Self-Determination for Youth with Disabilities: A Family Education Curriculum is composed of 15 modules, each of which covers an important aspect of self-determination by youth and young adults with disabilities:

- **Module 1: What is Self-Determination?** This module is designed to guide the family in creating a working definition of self-determination. The definition will be the foundation of their focus on enhancing the exercise of self-determination by the youth/ young adult with a disability.
- **Module 2: Creating a Personal Futures Plan**. The purpose of this module is to provide a process through which the young person with a disability (the focus person), working with other family members and significant others, can develop a vision and goals for his/her life based on the individual's capacities, values, and interests. As part of the discussion activities, the focus person and other participants describe the focus person's background and history, relationships, places he/she goes in the community and method of transportation, the choices he/she makes, preferences, and long- and short-term goals.
- **Module 3: Conducting Family Meetings**. The purpose of the family meetings module is to help the family members identify successful strategies for communicating with each other, making decisions, and discussing issues as a family unit. As part of the module, they are asked to identify how they currently conduct family meetings, evaluate what works and doesn't work in their meetings, and practice new meeting strategies.
- **Module 4: Identifying Values and Goals**. This module is designed to help the family identify what is important to their family as a group and to individual family members. The discussion activities are designed to enhance participants' understanding of the history of their family and individual values, and how these values impact their lives and goals.
- **Module 5: Recognizing Opportunities for Choice-Making**. The purpose of this choice-making module is to help family members identify how they make choices and how they might improve their choice-making skills. In addition, the module helps participants identify realistic opportunities for the focus person to use his/her choice-making skills and thereby take risks and build the self-confidence he/she will need when facing challenges in the future.
- **Module 6: Expanding Opportunities for Choice-Making.** In this module, participants identify ways to expand current opportunities for choice and self-determination within the family. Activities

include creation of choice maps documenting different types of choices each member makes, and discussion of ways to support increased choice-making by the member with a disability.

- **Module 7: Supporting Informed Choice-Making.** This module is designed to help families practice the skills for informed choice-making. These skills include supporting other family members, gathering useful information, and generating alternatives.
- **Module 8: Persevering in Choice-Making.** The purpose of this module is to help family members support each other in practicing choice-making, and persevering when choices don't work out.
- **Module 9: Realizing Your Vision**. The purpose of *Realizing Your Vision* is to help participants identify the long- and short-term goals and plans for the future of the focus person, as well as the behaviors, actions or steps necessary to reach those goals.
- **Module 10: Solving Problems**. This module examines the importance of problem-solving and explores the family members' personal and group problem-solving styles. The module reviews a series of effective steps to problem-solving, and discusses how participants can support each other when solving problems.
- **Module 11: Resolving Conflicts.** The *Resolving Conflicts* module focuses on identifying current methods family members use to resolve conflicts, and developing skills in successful negotiation.
- **Module 12: Advocating for Yourself.** The purpose of the personal advocacy module is to assist family members in defining what personal advocacy means for them, and identifying how participants can support each other in advocating for themselves in the family and the community.
- **Module 13: Connecting with Community Resources.** This module guides the family to a broader perspective on the resources in their community and how to effectively access them to support self-determination. In addition, the module can help the participants gain a broader understanding of how specific systems impact their family and individual lives, and how to effectively work within the systems to access resources, supports, and services when the need arises.
- **Module 14: Participating in Political Systems**. In this module, the family gains a broader understanding of how political systems can support self-determination and develops strategies for working with those systems to support the self-determination of family members.
- **Module 15: Continuing the Journey**. This module concludes the curriculum by reviewing key concepts, skills, and strategies and linking them in an overview of their role in ongoing support for self-determination by youth/young adults with disabilities.

Family Meetings

The family meeting brings all members of a family together to discuss concerns and experiences. Following the guidelines in this handout can help make the meeting a productive, positive experience for every family member.

Planning Your Family Meeting

When planning family meeting, decide what type of meeting it will be:

- Informational (share/give information)
- Discussion (brainstorming/feedback)
- Action (planning/problem-solving/decision-making)
- Combination

There are some pitfalls to avoid when conducting effective meetings. These include the following:

- Not knowing who is to run the meeting.
- Not knowing the agenda, what will be discussed.
- Holding meetings that are not needed.
- Selecting a poor time for the meeting.
- Letting the meeting become a gripe session.
- Failing to start and end on time.
- Neglecting to encourage participation by all individuals.
- Allowing interruptions.

Structuring the Discussion

Family meetings can be informal or formal in structure. The level of structure depends on family characteristics. Structure can range from an established agenda to an open opportunity for everyone to say what is on their mind. The same person can facilitate all meetings, or family members can share the responsibility. The following guidelines may be helpful in selecting a structure for family meetings:

- Understand the reason for a topic to be discussed. Why is it important to bring it up?
- Gather the background information. How long has this situation been occurring? Have family members share their history on the topic.
- Gather information about what is occurring at the present time.
- Clearly and concisely define the problem/issue so that all family members understand it. It may be good for the meeting facilitator

to write it down so all can see and keep track of the process.

- When information, history, and facts are gathered, move on to a problem-solving discussion in order to effectively deal with the topic.
- If a decision or course of action is not so clear, brainstorm possible solutions (Module 10 discusses how to brainstorm).

Facilitating the Meeting

The family meeting facilitator has two main tasks: (1) dealing with the subject and (2) dealing with the people. Dealing with the subject includes the following tasks:

- Making sure that all family members understand the issue and why it is being discussed.
- Structuring the discussion according to the guidelines listed on the previous page.
- Clarifying what is said in the meeting when someone appears to be confused or when statements are unclear. This includes making sure everyone is using the same definition of a word that has different meanings.
- Ending discussion about a particular topic if more facts are required, if family members need more time to think about it, if there is not enough time to discuss the topic, or if an issue can be settled by a couple of family members outside of the family meeting.

The facilitator's responsibilities in the area of dealing with the people include the following:

- Starting and ending the meeting on time. The meeting should not wait for latecomers; they will soon learn that if they want to participate in the entire meeting, they will have to arrive on time. Likewise, ending on time is important because meetings that drag on tend to be less productive.
- Encouraging and supporting the contributions of all individuals by expressing interest in their contributions. Respect should be shown for every family member's ideas, opinions, and suggestions, even those with which the facilitator disagrees.
- Encouraging the expression of different viewpoints, but intervening in personal attacks or finger-pointing. If attacking or blaming occurs, the facilitator can ask a question that requires a factual answer of a neutral member.

Closing the Meeting

Closure of the family meeting should consist of the following:

- Upon reaching a decision on the agenda topics, the facilitator should briefly summarize what has been decided.

- The members should develop an action plan for issues on which a decision could not be reached.
- The facilitator should confirm action individuals will take.
- The members should select a time, place, date, and possible agenda items for the next family meeting.
- A participant should write down what occurred in the family meeting and share this information with other members.

The material on conducting family meetings was based on Jay, A. (1976). How to run a meeting. ***Harvard Business Review, 54*** **(2), 43-57.**

4 Identifying Values and Goals

Introduction

What is a value? One way to define it is that it is a belief in the importance, worth, desirability, or goodness of certain principles or qualities. An individual's values determine what that individual identifies as important, what the persons' priorities are, how the person views the world and other people, and the goals the individual sets. Some values that people commonly hold are freedom, individuality, equality, economic security, honesty, and faith in a higher power. We learn our values from what we are taught and what we observe as children, and we revise them based on our life experiences as we grow older. Our values are part of who we are.

A goal is defined as something towards which a person's effort is directed. A person's values will shape what he/she identifies as being worthy of that effort. Setting goals helps individuals define what they want out of life and identify how to get it. Goals provide a standard against which individuals can evaluate the effectiveness of their actions and choices. Goals also serve as a source of motivation. Setting and working toward personal goals is one of the primary aspects of self-determination.

While every one of us has values and goals that are unique and personal, we may also have some that we share with other family members. Just as an individual's values influence his/her goals and decisions, so a family's values affect its goals and decisions. It is important to identify personal and family values and goals in order to discuss how they affect family life, how the family can support individual differences in values and goals, and how values and goals impact self-determination.

Overview of the Module

In this module, the family will participate in several activities to identify personal values and goals. They will learn the definition of *value*, how values are passed through generations, and identify the personal values of each family member along with values held by the family unit. They will also define *goal*, identify personal and family goals, and explore how goals are affected by values. This module is designed to be completed in one session of approximately two hours.

Module Goals

- *Family members will identify their individual and collective values and goals.*
- *Family members will discuss how, and to what extent, their values and goals interact to affect their self-determination.*

Module Objectives

- *The family will define values.*
- *Family members will identify both family and individual values, and how family history has affected the values.*
- *The family will demonstrate understanding of how some personal and family values can be the same and some different.*
- *The family will define goals.*
- *Family members will identify both family and personal goals.*
- *Family members will discuss how their values impact their goals, and how those goals affect self-determination.*

Module Activities

- *Community Meeting Follow-up*
- *Defining Values*
- *Family History*
- *Identifying Values*
- *Defining Goals*
- *Identifying Goals*
- *The Impact of Values*

Activity Plans

Activity 1: Community Meeting Follow-up

Introduction

The last activity in Module 3 was the opportunity for one or more family members to attend a meeting in the community and observe how the meeting was conducted. In this activity, those who attended a meeting will describe the meeting process they observed, and how it relates to their family meetings.

Materials Needed

None.

Preparation for Facilitator

None.

Preparation for Family

One or more members will attend a community meeting and observe the ways in which topics were discussed and decisions reached.

Instructional Procedure

- Ask if any family members attended a meeting in the community as part of the final activity in Module 3. If someone attended, discuss and document the person's observations of the community meeting: the way the meeting handled decision-making, how it facilitated everyone being heard, how it dealt with conflict, whether it was run by a single facilitator, etc.
- Discuss means to incorporate strengths observed in the community meeting into family meetings and how weaknesses observed in community meetings can be avoided by the family.

Activity 2: Defining Values

In this module, the family will identify the values and goals of each members and of the family as a whole.

Introduction

Before we can identify our values and goals, we must first define these terms. The purpose of this activity is to answer the questions, "What is a value?"

Materials Needed

Paper, pens, and pencils.

Preparation for Facilitator

At the end of the Module 3 session, ask family members to each make a mental list of his/her personal values. The family should also locate family memorabilia such as photos, videos, slides and letters that best reflect current family values and how they were formed.

Preparation for Family

Prior to session, each member should make a mental list of personal values. Also, locate family memorabilia such as photos, videos, slides and letters to bring to the family session. Try to locate memorabilia of people, places or things that best reflect current family values and how they were formed.

Instructional Procedure

- Introduce the *Identifying Values and Goals* module, and this activity, by explaining that every individual and every family has values and goals. These influence priorities and decisions, and are the basis for the choices we make. It is important to identify values and goals in order to discuss how they affect family life, how the family can support individual differences in values and goals, and how values and goals impact self-determination.
- Explain that in this activity the family will engage in a discussion to ensure that everyone in the family understands what a value is. Begin the discussion of values by asking the following questions:

  1) What is a value?

  2) What are some examples of values?
- Help family members identify the difference between values (beliefs) and things (tangibles) that are valued. If someone lists an item they value, ask them why they value that item. (Example: Money is a tangible that is valued, but the underlying value associated with money may be security, or freedom, or self-respect, etc.).

Review and Reflect

- How can you tell what a person's values are?
- How do his/her values affect a person's self-determination?

It may take some probing to identify values because many people are accustomed to thinking only about that which they can experience with their senses. Values are invisible, the ideals within our minds.

Activity 3: Family History

Introduction

Once we know what values are, we can begin to discover the family's values in more detail. The purpose of this activity is to show how values are shared and passed down through generations. The family will look at picture albums, photographs, videos, slides, letters, and other family memorabilia in order to gain a collective view of their history. The facilitator (or a family member) will draw a family tree during this activity to illustrate the discussion.

Materials Needed

Paper, pens, pencils,flipchart; family memorabilia; family tree diagram sample (see page 60 in the Supplemental Information at the end of this module).

Preparation for Facilitator

Become familiar with the family tree diagram (see page 60 in the Supplemental Information at the end of this module).

Preparation for Family

The family will find and bring memorabilia representing its values.

Instructional Procedure

- Explain that this activity is meant to help the family look at its history and identify how values are shared and passed down through generations by looking at memorabilia and talking about family members and events.
- Ask how the family would like to structure the discussion of memorabilia. Example: One member is the main spokesperson and 'handler' of the objects/items, with others adding to the discussion where they feel the need. Another example: All members of the family discuss their recollection of the item as it is presented and passed from one family member to the next.
- As the family shares memorabilia, ask them about their family history. They can either start at the beginning as far back as the family can remember, or go by generations describing what people did for a living, education, etc. Also ask the family to share stories that are a part of their family history or their current family.
- As family members discuss the family history, draw a family tree on the flipchart (see sample on page 60 at the end of this module). Note next to each name anything the family thinks is significant or memorable about the individual in relation to their values.

By becoming aware of common traits within the extended family and across generations, family members can better understand why the family today functions as it does and can make decisions about how it will be in the future.

Review and Reflect

- What are some general feelings you have about your family ancestors? Describe them in two or three words.
- Are those words true for your family today?
- What was the most impressive thing about your family history?

- What was the most humorous thing about your family history?
- Are there specific stories in your family that have been passed on through generations?
- Do you have stories from your current family?

Activity 4: Identifying Values

Introduction

Now that the family has examined its history in an attempt to find the historical roots of current family values, it is time to look directly at the current values. The purpose of this activity is to identify family members' personal values, and to identify the family's values.

Materials Needed

Paper, pens, and flipchart.

Preparation for Facilitator

None.

Preparation for Family

The family will bring examples of their personal values.

Instructional Procedure

- Explain that this activity is meant to help the family members look at their personal values, and to see if they can use their personal values to identify their family values.
- Providing paper and pens, allow family members to respond in writing to the question, "What is important to you?", or "What do you value highly?". Ask them to individually list all the ideas they can think of.
- Ask family members to prioritize or rank their lists of values in order of importance.
- Ask each member, starting with the member with a disability, to read as much of the list of personal values as he/she is comfortable sharing. Write each person's name on the flipchart, and list their values in order of priority.
- When all family members have listed their personal values, ask the family to discuss which of these values they feel are representative of the family's. Make a separate list of the family's values.

If the youth/young adult with a disability cannot write his/her own list of values, adapt the activity to facilitate that person's full participation.

Review and Reflect

- Are any family values affected by your family history?
- How does a piece of family historical memorabilia shared today relate to the values you hold personally?
- Is there one person from the past who had the most influence on your family's current values?
- In what situations have you talked about your values with your family?
- How are your personal values like your family's values? How are they different from your family's values?
- Point to a random value listed on the flipchart: Ask, "Does this value enhance or inhibit other family member's self-determination? Why or why not?"

Activity 5: Defining Goals

Introduction

To learn more about the connection between values and self-determination, we will now look closer at personal goals. How do we determine what our goals will be? Before we can identify our personal goals, we must first define the term. The purpose of this activity, therefore, is to define the term *goal*.

Materials Needed

Paper, pens, and flipchart.

Preparation for Facilitator

None.

Preparation for Family

None.

Instructional Procedure

- Introduce this activity by explaining that values affect goals. Before looking at its own goals, the family will first define *goal*. One possible definition is "Something you work to achieve." Goals are also of two types: short-term (achieved within a day or week) and long term (takes longer than a week).
- Ask the following questions:

1) How do family members define *goal*?

Each family member, starting with the youth/young adult with a disability, should be allowed to share his/her personal values without being criticized, challenged, or asked to defend them.

2) What are examples of goals?

3) What is the difference between short- and long-term goals?

- Ask each person to name one short-term and one long-term goal that they personally have. Write it on the flipchart under each person's name.

Review and Reflect

- How do an individual's goals affect his/her self-determination?

Activity 6: Identifying Goals

Introduction

Now that family members know what goals are, what are their personal goals? What are their family goals? This activity will help participants explore their goals.

Materials Needed

Paper, pens, markers, and flipchart.

Preparation for Facilitator

None.

Preparation for Family

None.

Instructional Procedure

- Explain that in this activity the family will identify long-term personal and family goals.
- Provide paper and pens, and ask family members to respond in writing to the question: "What are your long-term goals?". Ask them to individually list all they can think of.
- Ask each member to prioritize, or rank their goals from most important to least important.
- Ask each member in turn to read their list of personal goals (sharing only what they're comfortable sharing). Write each person's goals on the flipchart under his/her name and prioritized.
- When all members have listed personal goals, the family will discuss which of the goals they feel are representative of the family's goals. Make a separate list of these family goals.

By identifying their goals, family members will be able to see where their choices and values support their goals and where they may conflict.

Review and Reflect

- Has the family, as a group, ever discussed family goals?
- Does the family have goals? If yes, how do they match with the personal goals?
- Do family members ever discuss personal goals?

Activity 7: The Impact of Values

Introduction

The purpose of this activity is to identify how personal and family values affect the choices we make and the goals we set for ourselves.

Materials Needed

Flipchart, pens, and pencils. Flipchart pages from Activity 4 (the personal values of each family member).

Preparation for Facilitator

Read instructions, have materials listed above ready for use.

Preparation for Family

None.

Instructional Procedure

- Explain that this activity is meant to identify how our values affect the choices we make and the goals we set.
- Post the personal values list generated during Activity 4 to help family members remember what their personal values are, and the personal goals list from Activity 6 to help them remember their goals.
- Using those lists as reference points, ask each member to identify why their top goal was most important to them, and what personal values affected their choice of that goal?
- After all family members who wish to participate have done so, ask them if any of the values they have documented conflict at all with another family member's values. How were these conflicts resolved? Document these "resolutions" on the flipchart. (Note: These conflicts may be used for further discussion in the conflict resolution module).

For family members to receive the support they need in achieving goals, other members must recognize that each individual may, at times, be guided in a different direction by a different set of values than the rest of the family.

Review and Reflect

- How is an individual's self-determination affected by having the same values as the rest of the family?

- How is an individual's self-determination affected by having different values than the rest of the family?
- How can family members be supportive of each other's self-determination even if they hold different values?
- To enhance a family member's self-determination, what values might be important for a family to hold?

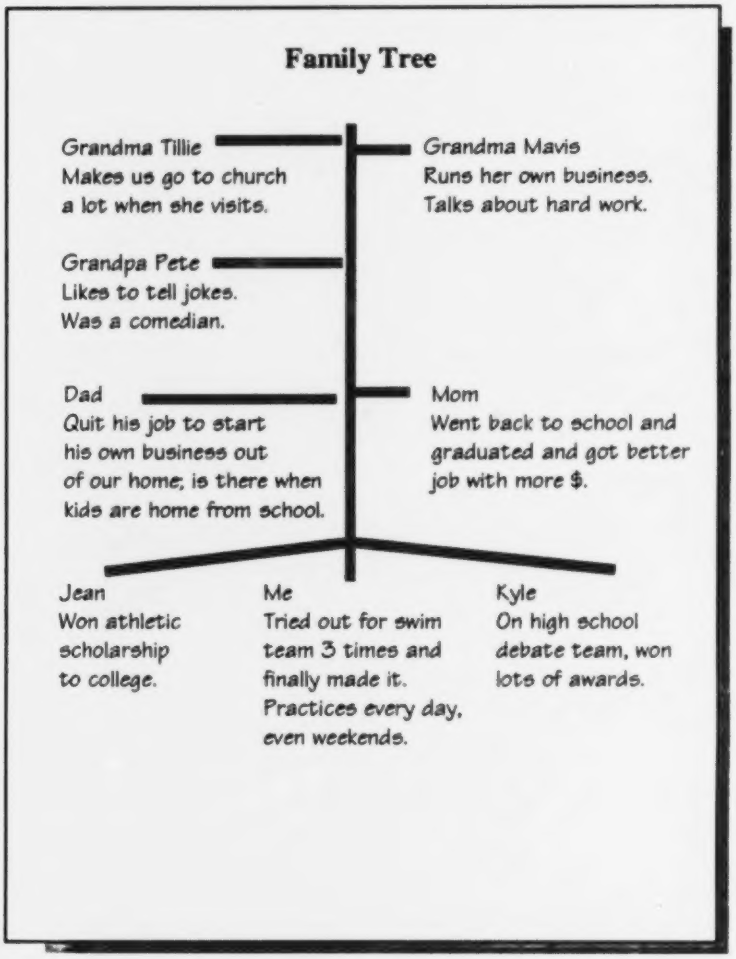
Preparation for Next Module

Distribute a copy of the handouts on decision-making and choice-making (see the Supplemental Information section, pages 68-73, at the end of Module 5) to each family member. There is one packet for all four choice-making sessions. Explain that this information may be reviewed throughout the session.

Identification of values and goals in this module leads to a fuller understanding of the choices family members make, the topic of the next module.

Family Tree Diagram

As the family names family members, past and present, during Activity 3, create a family tree on the flipchart that includes the name of the member, and anything that the family feels describes the person's significance in the family history, especially in relation to the family's values.



Family Tree

Grandma Tillie
Makes us go to church
a lot when she visits.

Grandma Mavis
Runs her own business.
Talks about hard work.

Grandpa Pete
Likes to tell jokes.
Was a comedian.

Dad
Quit his job to start
his own business out
of our home; is there when
kids are home from school.

Mom
Went back to school and
graduated and got better
job with more $.

Jean
Won athletic
scholarship
to college.

Me
Tried out for swim
team 3 times and
finally made it.
Practices every day,
even weekends.

Kyle
On high school
debate team, won
lots of awards.

5 Recognizing Opportunities for Choice-Making

Introduction

Each of us makes hundreds of choices every day, ranging from what to wear to what activities take priority over others. Every choice we make expresses our personality, values, feelings, and preferences. The opportunity to make choices provides us with the power to determine the course of our lives.

The acquisition of choice-making skills is a gradual process that takes place over an extended period of time. Developmental psychologists have accumulated evidence suggesting that parents who, while exerting some control, allow their children increasing freedom in a manner concordant with their abilities, produce offspring who are self-reliant, self-controlled, and cope well with stress. The passing of control from parent to child often occurs unconsciously for youth without disabilities and their parents. Most parents do not suddenly realize that they need to let their children exert more control over their lives; it just seems to happen. However, this is often not the case with parents of youth with disabilities. These parents may need to consciously decide to step back more and let the child decide for him/herself. They may need to be more explicit about the choice-making process, and set up situations in which the child has to make a choice.

The opportunity to exert choice and engage in decision-making within the context of family relationships provides children and youth with or without disabilities the chance to practice skills that will eventually allow them to exert control over their lives as adults. Developmental outcomes as diverse as achievement motivation, independence, warmth, and responsibility have all been linked to family interaction and parenting that allows for personal choice. Due to the characteristics inherent in many disabilities and the assumptions that members of society often make about persons with disabling conditions, children and youth with disabilities often do not experience many opportunities for choice outside the family setting. This magnifies the importance of the home environment in fostering the development of skills necessary for self-determination.

Overview of the Module

This session is designed to increase awareness of opportunities for making choices, and to provide a venue for discussion about the choices that are available for each family member. The module is designed to be completed in one session of approximately two hours.

Module Goals

- *The family will work together to increase recognition of choice-making opportunities.*

Module Objectives

- *The family will understand what a choice is, and will identify long-term and daily choices.*
- *The family will recognize choices that individual family members make independently, and choices they make with others (other family members, friends, coworkers, teachers).*
- *The family will recognize how each individual's choices may affect others.*
- *The family will discuss their ideas of appropriate choices for members of different ages.*

Module Activities

- *Advantages and Disadvantages of Choice-Making*
- *Current Choice-Making*
- *Age-Appropriate Choices*
- *Children Assign Family Chores*

Activity Plans

Activity 1: Advantages and Disadvantages of Choice-Making

Introduction

Choice is important to self-determination. This discussion provides a setting for open communication between family members about the advantages and disadvantages of choice-making.

Materials Needed

Paper, pen, and pencils; handouts on choice-making (see pages 68-73 in the Supplemental Information at the end of this module).

Preparation for Facilitator

- At end of the previous module session, distribute a copy of the handout on choice-making (see pages 68-73 at end of this module) to each family member. There is one packet for all four choice-making modules. Explain that this information will be used throughout the next four sessions.

Preparation for Family

- Read the handout on choice-making distributed at the end of the previous module session (see pages 68-73 in the Supplemental Information at the end of this module).

Instructional Procedure

- Introduce this module and activity by describing the importance of choice-making in healthy human development and the additional attention that young people with disabilities may need to acquire choice-making skills (base your comments on the information in the Introduction to this module on page 61). Explain that this activity is meant to help the family look at the advantages and disadvantages of choice-making.

One of the first steps in increasing choice-making is recognizing the many opportunities available for making choices. If a youth/young adult doesn't know which situations offer choices, it is difficult to imagine that he/she will make choices.

- Ask the adults to think of and write down reasons all family members should be able to make choices. At the same time ask younger members of the family to work together and write down reasons that all family members should not be able to make choices.

- Begin a discussion of the positive aspects of choice-making and negative aspects of choice-making, asking participants to read and, if necessary, support their reasons. Ask questions such as, "Was it difficult to come up with your argument in support of each reason?", "Do you agree with your argument?", " Do you agree with any of the other side's reasons?", and " What, if anything, have you learned from the activity?". You may want to refer to the handout, *Arguments For and Against the Right to Make Choices* (see page 70 in the Supplemental Information at the end of this module).

Review and Reflect

- How does this activity affect your opinion about choice-making for the members of your family?

Activity 2: Current Choice-Making

Introduction

Before discussing what changes might be made to insure more opportunities to make choices, it is useful to know how choices are already being made within the family. Is one person in charge, and information trickles down? Is communication clear? Answering these questions gives good background information that can help families become more self-determined and make the choices they want to make. The purpose of this activity is to look at the way a family currently makes choices.

Materials Needed

Pencil and paper to record observations, a camcorder (optional) to document the activity; handouts on choice-making (see pages 68-73 in the Supplemental Information at the end of this module).

Preparation for Facilitator

- At end of the previous module session, distribute a copy of the handout on choice-making (see pages 68-73 in the Supplemental Information at end of this module) to each family member. There is one packet for all four choice-making modules. Explain that this information will be used throughout the next four sessions.

Preparation for Family

- Read the handouts on choice-making distributed at the end of the previous module session (see pages 68-73 in the Supplemental Information at end of this module).

Instructional Procedure

- Explain that this activity is meant to help the family get a better look at how it currently makes choices together. Set the stage for this module by reviewing and discussing applicable material from the handout on choice-making that was distributed at the end of the previous module.

How does the family currently make choices, both as a unit and as individual members?

- Introduce role-playing of choice-making scenarios as a technique for exploring opportunities for choice. Ask the family to read a choice-making scenario out loud and then role play how they would go about making the choice. While the family is doing this, one facilitator will unobtrusively write down observations of the family's choice-making process and style. (If all the equipment is available, and the family is comfortable with being videotaped, you may videotape the choice-making activity. The choice-making scenarios are:

  1) It is Friday night and your family is at home. Everyone has said they would like to do something in the community after dinner with the family. Demonstrate how this decision would be made.

  2) The family is planning on spending the day together this Saturday. Demonstrate how the family would decide what to do for fun.

  3) Your family is throwing a Halloween party for family friends. Demonstrate how your family will decide who to invite.

  4) Your family is planning on taking a family vacation next summer. Demonstrate how your family would decide where to go on vacation.

- If the role play was videotaped, view the tape. If it was not videotaped, review your observations and notes. Based on the tape or the observations, correct perceptions and fill in missing information during discussion of the following:

  1) What is the first step your family took when making the choice?

  2) Who had the most say when your family made the choice?

  3) Ask each family member: What part did you play when your family made the choice?

  4) Does your family make all choices the way you made this choice?

Review and Reflect

- How will the ways your family makes choices be changed as a result of this activity?
- How could this activity help your family make more choices?

Sometimes parents and other caregivers need to learn which choices and responsibilities are manageable for young people at different developmental stages.

Activity 3: Age-Appropriate Choices

Introduction

In this activity, participants examine the way different choices become available with increasing age and maturity. Although the idea that increased maturity provides increased choice opportunities may seem obvious to adults, children may not see the relationship. This activity will help families discuss the reasons for differences in choice opportunities for children of different ages. It will give the family a chance to discuss their opinions about what choices are available and appropriate for each child.

Materials Needed

Flipchart and markers to document the discussion.

Preparation for Facilitator

Read the scenarios listed below.

Preparation for Family

None.

Instructional Procedure

- Explain that the purpose of this activity is to discuss what the family thinks are age-appropriate choices.
- Tell participants that they can give their responses in a round-robin format, which will be documented on the flipchart.
- Put the heading "Elementary School" on the top of the flipchart, and ask the family to give examples of choices a person in elementary school can make *on their own*. Then ask the family what choices a person in elementary school can make *with the help of someone else.*
- Repeat the above steps for several different ages, such as "Junior High," "Senior High," and "After Graduation".
- Read the following choice-making scenarios, ask the family how old they think a person should be before they can/should make the choice. Document their answers on the flipchart:
  1) The person chooses what to eat for snacks.
  2) The person chooses to stay overnight with a friend.
  3) The person chooses to stay out all night.
  4) The person chooses to go out on a date.
  5) The person chooses to go to college.
  6) The person chooses to get married.
- Ask parents how the choices they had when they were children are similar to the choices their children make.
- Ask children how a disability affects the choices mentioned in the activity.

As children and youth increase in maturity and abilities, their options, freedoms, and responsibilities should also increase. This may be a new way of thinking for some parents and caregivers of young persons with disabilities.

- Ask parents and children if they can think of choices that kids of certain ages should not make?

Review and Reflect

- How is self-determination affected by your age?
- How are opportunities for choice different as you get older?

Activity 4: Children Assign Family Chores

Introduction

Sometimes adults lose perspective about what it is like to be a child or young adult and have decisions made for you. This activity is designed to provide a role reversal: the children assign chores for the whole family. Families may decide to do this activity only during the session. Another option is for families to follow through with the assigned chores for a week and regroup to discuss how it felt. The purpose of this activity is to help family members feel what it is like to have decisions made for them. An assumption about this activity is that the parents decide what chores the children do. If this is not the case, this activity can be adapted to address another area in which the parents decide what the children will do.

Materials Needed

Pen, paper, flipchart.

Preparation for Facilitator

Be prepared to keep the discussion on topic, and to facilitate clear communication.

Preparation for Family

Put together a list of jobs or chores that need to be done around the house.

Instructional Procedure

Children and adults can learn to understand each others' feelings and perspectives by exchanging roles, such as in Activity 4.

- Explain that this activity is meant to help the family get a better look at what it feels like to have someone else make choices for them.
- Ask the family as a group to generate a list of the household chores that must be done at least once a week.
- Write down all the names of family members on a flipchart.
- Tell the children in the family that they are going to be in charge of assigning the jobs. Give them the one constraint: every member of

the family must have a job assigned to them before any member can have two jobs assigned to them.

- Ask each young person to assign a job to the family member they choose. Write down the assignments on the flipchart.
- After all the chores have been assigned to family members, explain that for the upcoming week, household chores will be completed by whomever the young people selected.
- Discuss participant reactions. Ask participants what they thought of the way these choices were made, how the assignments differed from the usual, and how it felt to be assigned a job.
- If the family decides to do the assigned chores, ask them to think about these questions, which they will discuss at the next session: "What did you learn from this activity?", "How did you feel when you were assigned chores or when you were assigning chores?", "How did it feel to do something you didn't have a choice about for one week?", and "What if you had to do it longer?".

Review and Reflect

- How is self-determination different from having choices made for you?
- After meeting with a facilitator, families may be interested in continuing to meet together, with or without a facilitator. Some ideas for family meetings that relate directly to recognizing opportunities for choice are listed below.

  1) Family members can think about the choices they make each day and write down the ones they feel the best about.

  2) Family members can pick one hour of the day (or 30 minutes of the day), and count the number of choices they make in that amount of time. This can be done together with another family member, or individually.

  3) Family members can identify choices made by characters in stories or on TV. These examples can be written down or shared verbally at a family meeting.

Preparation for Next Module

- The family should review the handouts on choice-making (see pages 68-73 in the Supplemental Information at the end of this module) before the next session.
- The family may choose to carry out the chores as assigned, and discuss the results in the next session.

Acknowledging that choice-making is important for everyone and that there are opportunities for everyone to make decisions sets the stage for looking at additional ways to create choice-making opportunities, the topic of the next module.

Supplemental Information

This information provides the background for the activities and discussion in modules five through eight on choice-making. Both the facilitator and family members should read it prior to participating in the first choice-making module.

Families as Decision-Makers

One of the most important decisions a family must make is **deciding how to decide!** Unfortunately, this crucial determination is frequently overlooked or made in haste when a critical issue involving great risk is at hand.

There is no one perfect style or form of decision-making. In fact, decision-making methods will vary, depending on the level of involvement of those persons who will be directly affected by the decision. No single method of decision-making is ideal. It depends on the situation. Decisions can be made by:

- One person, without input from anyone else.
- One person, with input from others.
- An expert on the question being considered.
- A majority vote.
- A consensus.
- A family (working toward a goal).

Within each family there are different systems that are capable of making decisions:

- An *individual* decision made within a family system is a decision that can be made alone. However, one must realize that all decisions will affect other family members. For example: If an 18 year old decides to come home at 4:00 am this decision affects the parents.
- A *subsystem* decision is a decision that is made between two or three people rather than the whole family. For example: A daughter decides with her mother how to get her hair styled without asking her father for advice.
- A *system* decision involves the entire family. It usually takes more time and energy to reach agreement when the whole family is involved, but the extra time and effort will be offset by the good will and effectiveness with which the decision will be implemented. When the entire family is involved in decision-making, the decision can be reached by majority vote or by consensus. The wise family deliberates carefully as to when the consensus of the entire family should be sought and when this process may be very inefficient. The consensus method is most effective when the family has reached the stage of development where individual

differences are not only tolerated, but welcome, and there is a high level of trust. However, for those decisions that are less important, when family members lack relevant expertise, and when implementation does not require full cooperation, it is more appropriate to use one of the less time consuming methods of decision-making.

One should not anticipate that everyone will be happy with decisions made by the family. Conflicts within a family are often the cause of one person making a decision that affects other family members without input from the rest of the family. However, even in families using a system decision-making process there is still going to be conflict.

A positive approach to conflict should be one that makes use of it as a means of building trust, creating innovative solutions to problems, and strengthening relationships. Addressing conflicts must be done constructively, otherwise, the opposite may occur, generating distrust, destroying relationships, and stifling creativity. It is important that conflicts be acknowledged and dealt with; conflicts that remain under the surface tend to erupt in very unpredictable and destructive ways.

Decision-making and conflict resolution sound like a lot of work **because they are**! It can be frustrating for a family to focus on process; but getting to know how to work together, is the most effective way to build and sustain a family. Knowing how to do it isn't enough. You must experiment with the process. Make mistakes, learn from them, and become a more empowering, capacity-building family. The process takes courage, creativity, and commitment, as well as skills.

Adapted from Matusak, L.R. (no date). Leaders as decision-makers. *KMFP Focus*, Battle Creek, MI: W.K. Kellogg Foundation.

Arguments For and Against the Right to Make Choices

Arguments For the Right to Makes Choices

- All people are guaranteed the same basic rights, including persons with disabilities.
- Everyone has the right and ability to make some degree of choices.
- Persons with disabilities should be able to exercise as much choice as their abilities allow.
- Being able to make choices prepares persons with disabilities to live in the community, where individuals are expected to make their own choices.

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Arguments Against the Right to Make Choices

- People with disabilities may make choices that others view as inappropriate according to a double standard. For example, a person with a disability taking a nap or watching television during free time may be labeled "lazy", while a nondisabled person engaging in the same behavior is "relaxing."
- Having the freedom to make choices may hinder the acquisition of independent living skills by persons with disabilities. For example, a person with a disability may choose to have a parent drive them to work rather than learn how to take the bus. Some people believe that restricting choices is appropriate in order to teach independent living skills.

Adapted from Bannerman, D.J., Sheldon, J.B., Sherman, J.A. & Harchik, A.E. (1990). Balancing the right to habilitation with the right to personal liberties: The rights of people with disabilities to eat too many doughnuts and take a nap. *Journal of Applied Behavior Analysis, 23,* 79-89.

Facilitating Choice-Making

Exposure to New Situations

As young people mature, they will be exposed to situations that will require them to make choices and abide by consequences. One way to help prepare children to take advantage of these opportunities in the future, is to allow for exploration of new environments and situations when they are young. It is during these times that young people begin to learn more about their own capabilities and limitations and to feel a sense of autonomy. Early exposure to choice-making and the opportunity to take risks can help build the self-confidence needed to face challenges in the future. (From Mitchell, B. (1988) Who chooses? In *Transition Summary, 5,* 4-5. National Information Center for Children and Youth with Handicaps.)

Consistent Expectations

The importance of receiving the message that those who care about you have faith in your ability not only to succeed, but also to survive a failure, cannot be overstated. Having a 'good failure' or making a 'bad choice' is something everyone should experience. To know that it is a normal part of life and people still care about you and believe in you, can encourage you to continue to make choices. Another effect of this kind of early learning is a sense of feeling more in control of your own destiny. (From Mitchell, B. (1988) Who chooses? In *Transition Summary, 5,* 4-5. National Information Center for Children and Youth with Handicaps.)

Stable Support Systems

To be more comfortable in taking risks, it is helpful to know that you've got a place to come home to after it is all over. For parents this means trying to provide stability and security for young people to the greatest extent possible, while also giving them the freedom to explore. Young people who are beginning to cope with increasing responsibilities and who are feeling overwhelmed by their choices can ease their anxiety by looking for small ways to bring stability to their world. (From Mitchell, B. (1988) Who chooses? In *Transition Summary, 5,* 4-5. National Information Center for Children and Youth with Handicaps.)

Choice as an Expression of Autonomy

In the course of a day, most of us make hundreds, if not thousands of choices. Some may be as insignificant as whether we will have yogurt or cereal for breakfast, while others may have broader implications such as whether or not we will quit our job, buy a new car, or move to another city. Each choice we make is an expression of our personal autonomy - our freedom to define who we are and what we value. The opportunity to make choices provides us with power to determine, to a great extent, what happens to us on a moment-by-moment basis as well as over the span of our lives. To have the power to make choices taken away would, for many of us, be devastating if not unbearable. (From Guess, D., Benson, A., & Siegal-Causey, E. (1985). Concepts and issues related to choice-making and autonomy among persons with severe disabilities. *Journal of the Association for Persons with Severe Handicaps, 10* (2), 79-86.)

Choice as Independence

For all of us, the ability and opportunity to make choices is an important and cherished component of our lives. Our opportunity to make choices reflects favorably on or perceived independence, dignity, and self-worth. We both protect and value our options to choose. Independence, therefore, involves living one's own life the way one wants to live it within one's ability to do so and in a way that is consistent with one's own values and preferences.

Independence is more than physical or psychological capacity, the doing of tasks without assistance. It can mean choosing to do tasks with assistance, to be dependent or interdependent. It can mean choosing who to depend on, or when to depend on them. (From Turnbull, A.P. & Turnbull, H.R. (1985). Developing independence. *Journal of Adolescent Health Care, 6,* 108-120.)

Choice as Responsibility

Responsibility has been defined as "caring for the consequences of our acts." Most parents want their young people to be responsible and to be able to make constructive choices. Educators, too, are concerned about the development of decision-making skills and responsibility in their students. What parents and teachers should keep in mind is that most young people assume responsibility well when the situation in question has real significance to them.

Parents and educators can help adolescents strengthen their skills by providing them with opportunities to make decisions and assume responsibility - which isn't always easy! At times parents and teachers may feel it's simply easier to do something themselves. Occasionally egos get in the way, since there is some risk in a job being done poorly by letting an adolescent assume major responsibility for its completion. Adults may regard it as their failure if the adolescent doesn't succeed.

There is, however, something to be said for helping young people learn to lose or fail with grace. Being able to accept failure, to pick one's self up and go on from there is one form of assuming responsibility.

There is payoff for both adolescents and adults if young people learn to accept responsibility for their behavior and to make constructive decisions. For adolescents it can be academic achievement, peer recognition, better relationships with parents and siblings, income from a job, personal satisfaction, and growth in self-esteem. On a long-term basis the payoff can mean a life-long vocational skill, increased ability to cope with life's circumstances, personal enrichment, and a happier, more productive life. (From Rowe, John (1981). Enhancing adolescent responsibility - the fourth "R". *The High School Journal, 64*, 249-56.)

Steps of Effective Choice-Making

Step 1: Identifying the Choice to be Made

The first step in effective choice-making is identifying what the choice might be. Sometimes there are several choices that need to be made, one leading into the next. Sometimes choices are made one at a time.

Step 2: Identifying Who Should be Involved in Making This Choice

Although most choices may seem to be made by one person, many choices involve several people. A person making a choice must be able to recognize: (1) when others need to be involved in the choice-making process, and (2) when others need to be informed when a choice is made. For example, if a person living at home with his/her family decides to skip dinner or stay out later than usual, these decisions affect other people. Identifying who should be involved in making the choice is important before any choice is made because it increases the probability that the decision you make is the right one for you.

Step 3: Identifying Alternative Choices

This step may seem the same as the first step, but it is not. In the first step, you try to be very specific (identifying the choice to be made); now you want to see if there are other possibilities for you to consider. Sometimes you can think of alternatives to your first choice that might be easier or result in more positive consequences.

Step 4: Identifying Positive and Negative Consequences

Another critical aspect of effective choice-making is being able to identify what are positive and negative, good or bad, beneficial or detrimental consequences. Knowing how many and what these consequences are, should guide your decisions. What makes a choice a good one? What makes a choice a bad one? Usually we judge a choice in terms of its consequences. If we don't see something positive as a result of our choice, or something negative happens, we usually say that the choice was a bad one. If something positive occurs as a result of a choice, we generally say it was a good choice. These views of what is good and bad come from a number of sources, including our home, school, neighborhood, culture, religion, town, state, and country.

Step 5: Selection of Choice

Once you have identified the choice, who should be making the choice, the alternatives, and the positive and negative consequences of each alternative, you are ready to make a selection. This step can not be left out or a choice would never get made.

6 Expanding Opportunities for Choice-Making

Introduction

Increasing opportunities for choice may seem like a minor issue, but if you are the individual who has been limited by erroneous assumptions about your capabilities, it could be a very big deal! In recent years, researchers have found that young people with mental retardation, emotional/behavioral disorders, physical disabilities, or learning disabilities, at all levels of severity, do have the capacity to exercise control over their lives by making choices. This is not to imply that all individuals have the capacity to take complete control over their lives. It is unlikely that persons with severe cognitive disabilities, for example, will develop the capability to independently make major decisions about their educational programs or their medical care. If one is persistent, however, and provides the individual with creative alternatives for involvement in decision-making, the majority of persons with even the most severe disabilities will be able to actively contribute to choices that will impact their lives.

To make "good" choices, many persons with disabilities will need specific instruction in skills such as goal-setting, prioritizing, problem-solving, information-gathering, and generating and selecting alternatives. All the skills in the world, however, will be of little use if the individual does not get a chance to use, practice, and refine them in supportive home, school, and community settings. Unfortunately, many persons with disabilities are either never given these opportunities or don't have them made available until they reach adulthood. By that time, the choices one has to make have become quite complex. Through becoming more adept at providing valued, age-appropriate opportunities for choice and supporting the development and use of skills in this area, families will increase the degree of personal control exercised by youth/young adults with disabilities as they enter the adult world.

Overview of the Module

In this module, participants identify ways that current opportunities can be expanded to provide even more opportunities for choice and self-determination within the family. The family will make choice maps and based upon the maps discuss ways that they can support increased opportunities for choice-making by the member with a disability and other family members. This module is designed to be completed in one session of approximately two hours.

Module Goals

- *The family will enhance choice-making in areas it identifies.*

Module Objectives

- *The family will work together to help increase each family member's influence or degree of control in present choices.*
- *The family will discuss the advantages and disadvantages of enhanced opportunities for choice-making.*
- *The family will discuss possible future residential options for young adult family members.*

Module Activities

- *Follow-up to Children Assign Family Chores*
- *Making Choice Maps*
- *Independent/Interdependent Choice-Making*
- *Enhancing Current Choices*

Activity Plans

Activity 1: Follow-Up to Children Assign Family Chores

Introduction

The final activity in Module 5 was for the children in the family to assign chores for all the family members, and for the family to carry out those chores for a week. This activity gives the family an opportunity to discuss what happened as a result of that activity and what they learned from it. If the family did not choose to carry out the chores as assigned, go to Activity 2.

Materials Needed

List of assigned chores from Module 5.

Preparation for Facilitator

None.

Preparation for Family

Do assigned chores for a week; bring list of chores to this session.

Instructional Procedure

- Ask the family to review the chore assignment and describe, in general, how the role reversal went. Discuss the following questions:

  1) What did you learn from this activity?

  2) How did you feel when you were assigned chores or when you were the one assigning the chores?

  3) How did it feel to do something you didn't have a choice about for one week?

  4) How would you react if you had to do those chores longer than a week?

Review and Reflect

- How has that activity changed your thinking about having choices made for you or making choices for others?
- How does making choices for yourself affect self-determination?

In this module, the family identifies ways that current opportunities can be expanded to provide even more chances to exercise self-determination and choice-making within the family.

Activity 2: Making Choice Maps

Introduction

A choice map is a concrete way to see all the different types of choices that an individual makes: independent choices, choices made with assistance, and choices made by others for him/her. The purpose of this activity is to make a chart or choice map documenting the choices that all family members make. In terms of self-determination, it would be most appropriate if very few choices were made for a person, and as many choices as possible are made by the individual. Of course, every individual is unique, and every family has unique ways of handling choice-making. The intent is not to judge the ways choices are being handled, but to provide information for review and perhaps change.

Materials Needed

Pencil or pen and large pieces of paper or a flipchart; choices map from Module 2.

Preparation for Facilitator

Review choices map from Module 2.

Preparation for Family

Review choices map from Module 2. Think about examples of choices each family member makes in his/her life, and choices that others make for him/her.

Instructions for Facilitator

- Introduce this module and activity by describing the importance of adequate opportunities to make choices, especially for youth/young adults with disabilities (base your comments on the information in the Introduction section of this module on page 75).
- Explain that the purpose of this activity is to diagram choices that family members make independently and choices that they make with others. This is a repeat of the process used for the focus person in Module 2.
- Review the focus person's choices map from Module 2. Ask if there are any changes that should be made to update it.
- Ask if someone would like to start. Write the person's name on the top of the flipchart and make three columns below it - "choices made by _______," "choices made by ______ and others," and "choices made by others".
- Begin by asking the person what choices fall under each category. List them on the chart.

By expanding the choice mapping to include all family members, this activity helps the family create a home environment where everyone has the maximum opportunity for making choices.

- When the person has given all of their responses, ask family members if they have anything to add.
- Repeat the above steps for each family member present.
- Ask participants what they've learned from the choice map activity. If a discussion is not easily generated, ask each family member a question in a round-robin style. Possible questions include: "How happy are you with the choices you make?", "How do different family members' choice maps compare with each other?", and "Are there more choices you would like to make?".

Review and Reflect

- How does having these choice maps change the way you think about the opportunities you have to make choices?
- How will you use this information?

Activity 3: Independent/Interdependent Choice-Making

Introduction

Understanding why some choices are made independently and others are not can be a volatile topic. Understanding the perspective of a parent or child is important when families are deciding how to provide opportunities for making choices. The purpose of this activity is to look at why some choices are made independently or with the help of others.

Materials Needed

Paper and pen or pencil.

Preparation for Facilitator

Have choice maps from Activity 2 available.

Preparation for Family

None.

Instructional Procedure

- Explain that this activity is meant to help the family look at why choices are made with other people or made independently.
- Ask if someone would like to start (if no one volunteers, ask a parent if they would like to start). The family member who goes first looks at his/her choice map and picks one choice listed in each of the three categories.

Often it is assumed that people with disabilities cannot make good independent choices. It is important for the other family members to look at their assumptions and actions that encourage or discourage independent choice-making by the young person with a disability.

- Ask the person why each choice is made the way it is. If a choice is made collaboratively, ask who helps the person make the choice.
- Ask the rest of the family if they have anything else to add. Write down the family's responses.
- Repeat the above steps for whomever wishes to participate.
- Ask participants if there are there some choices they make with someone that they would rather make alone. Are there some choices they make alone that they would like some help with?

Review and Reflect

- How are the choices you make affected by others?

Activity 4: Enhancing Current Choices

Introduction

In the Personal Futures Plan (Module 2) and Activity 2 of this module, choice maps were made for the focus person and other family members. In this activity, the family will use their choice maps to generate ideas for new or enhanced choices for all members of the family who feel that they are capable of making more choices than they are currently offered. The focus person and the family will generate an action plan to provide the focus person with enhanced opportunities for making choices in one or more areas of his/her life.

Materials Needed

Paper, pen, and pencils; handouts on choice-making (from Supplemental Information on choice-making at end of Module 5); choices maps from Module 2 and from Activity 2 of this module.

Preparation for Facilitator

Bring the choices map from the Personal Futures Plan (Module 2) of the focus person to use in the activity, along with the choices maps of other family members generated in Activity 2 of this module.

Preparation for Family

Review handout on choice-making (see Supplemental Information in Module 5); bring the choice map from the Personal Futures Plan, and have available the choice maps done earlier in this module.

Instructional Procedure

- Explain that this activity is meant to help family members think of ways they can support the focus person in increasing or improving his/her choice-making.

Looking at the current situation is the first step toward change; the next step is to plan for change.

- Create a chart depicting various "domains" in which the focus person finds him/herself on a daily basis, such as home, school, and in the community. Briefly describe each. Using the choice map, list the choices from the map under each domain.
- Ask the focus person for ideas of areas in which he/she would like to make more choices or make more independent choices. Write these ideas down.
- Ask the other family members if they have ideas of other areas where the focus person could make more choices or more independent choices. Write these down.
- Ask the focus person to prioritize the ideas on the list. If there are more than five, ask for the top five. After the focus person has responded, have the other family members give their priorities for the focus person. If there is a discrepancy between the two, discuss and try to reach consensus.
- Brainstorm with the other family members ways that they can support the focus person's choice-making in his/her priority areas.
- Select one of the priority areas and generate an action plan to enhance opportunities for choice in this area. Develop a contract that states each party's role in this commitment to active support of choice-making.
- If there is time, repeat this process for other family members using their choice maps. If there isn't time during the session, recommend that family members do the process together at home.

Review and Reflect

- What will the focus person gain from the enhanced choice-making opportunities? What will be difficult about the expanded choices?
- How will enhancing opportunities for choice change the choices that are made (either the quality or number of choices)?
- How will enhancing opportunities for choice-making affect self-determination?

Increasing opportunities for choice-making goes hand-in-hand with acquiring and practicing skills for successful choice-making, the topic of the next module.

Preparation for Next Module

- Ask each family member to think of three or four choices they make in their lives, such as what to wear, where to take a vacation, or how to spend free time. Every member should come to the next session with at least two choices to discuss. Each should also identify two new choices they would like to make in the future.
- Prepare cards listing choice-making scenarios (see pages 83-84 for scenarios) to use during the next session.

7 Supporting Informed Choice-Making

Introduction

One of the most important components of self-determination is choice-making. For choice-making to enhance self-determination, however, one's choices must be based on more than merely flipping a coin or impulsively selecting the first option that comes to mind. The choices one makes must be *informed* choices.

Informed choice-making is based on awareness, understanding, and careful consideration of the possible options and probable outcomes. For a variety of reasons a youth/young adult with a disability may be unaware of the alternatives from which to choose, fail to adequately understand the impact of potential decisions on him/herself and others, not know how to obtain the information necessary to make an informed choice, or fail to generate sufficient alternatives prior to making a decision. Youth/young adults with disabilities need the support of their families if they are to learn to make decisions that truly reflect their own preferences.

The roles that families can play in supporting informed choice-making include serving as resources for information, encouraging step-by-step choice-making, assisting in brainstorming, and providing feedback. However, family members must be careful to strike a balance between providing support while at the same time not unduly influencing the individual. The key is to learn when support is needed and then develop strategies that empower the individual with a disability to independently make choices that reflect personal preferences.

Overview of the Module

This module is designed to help families practice skills useful for informed choice-making. These skills include supporting other family members, gathering useful information, and generating alternatives. Two activities are designed to examine how the family currently responds to and supports other family members' choices and how they can improve in that area. The other activities examine ways that the family can enhance its ability to gather information and generate alternatives. This module is designed to be completed in one session of approximately two hours.

Module Goals

- *The family will discuss ways to support informed choice-making.*

Module Objectives

- *Family members will recognize how they respond to each other's choices.*
- *Family members will learn how they can share information when other family members are making choices.*
- *Family members will develop ways to honor/respect each other's choices.*
- *Family members will explore ways they can support generating alternatives.*

Module Activities

- *Responding to Others' Choices*
- *Identifying Information for Making Choices*
- *Supporting Other's Choices*
- *Generating Alternatives*

Activity Plans

Activity 1: Responding to Others' Choices

Introduction

The purpose of this activity is to discuss how family members respond to each other's choices. It is designed to promote communication about how family members react to choices made by other family members. It may reveal patterns individuals have not been aware of, such as sending negative messages without realizing it or unconsciously encouraging certain choices.

Materials Needed

Paper and pens.

Preparation for Facilitator

None.

Preparation for Family

Each family member should think of three or four choices they make in their lives, such as what to wear, where to take a vacation, or how to spend free time. It is important for all family members to come to the session with at least two choices they make.

Instructional Procedure

- Introduce this module and activity by describing the importance of having support for gathering information when making choices (base your comments on the information in the Introduction to this module on page 81). Explain that this activity is meant to help the family identify how they respond to each other's choices.
- Ask for a family member to start. The person who begins will give an example of a choice they make, and will describe how family members respond to the choice. Examples of possible choices are the clothes a person chooses, what a person chooses to do for fun, how a person spends money, and the friends a person chooses.
- Ask if anyone else in the family has anything to add.
- Repeat for anyone who would like to share a choice they make and how the family responds to it.
- Discuss the following: Are family members happy with the way others respond to their choices? Were family members surprised by how anyone described the way members respond to their choices? Do members ever regret the way they respond to a family member's choice?

This module is designed to help families practice skills useful for informed choice-making.

Review and Reflect

- How does this activity change the way you might encourage self-determination?
- How might knowing how others respond to your choice affect how you make choices in the future?

Activity 2: Identifying Information for Making Choices

Introduction

One way to effectively facilitate and support others' choices is to help them understand the situation. In order to make informed choices it is important to know what information is needed. This activity is designed to help family members identify the information they need when assessing a situation.

Materials Needed

Paper, pencil or pen; note cards with choice-making scenarios written on them (example: "You are going to the beach tomorrow; what information will you need, so you will know what to wear?").

Preparation for Facilitator

Bring cards with choice-making scenarios.

Preparation for Family

None.

Instructional Procedure

- Explain that this activity is meant to help the family identify *when* information is needed to make a choice and *what* information is needed to make the choice.
- Each family member will take a turn picking a scenario card. One family member will read the card and make sure everyone understands it. Each family member will give their idea of one piece of information that is needed to make a choice in the scenario. Write down the family's ideas. The choice-making scenarios are:

  1) You are going to the beach tomorrow. What information will you need so that you will know what to wear?

  2) You have been invited on a ski trip with a family friend. What information will you need before you decide what to bring on the trip?

Part of strengthening self-determination is to encourage the young person with a disability to speak for him/herself in these activities.

3) You are having a party at work/school and you are going to bring the party supplies. What information will you need to know before you decide what party supplies to bring or buy?

4) You are buying a birthday gift for your next door neighbor. What information will you need before you decide what to give him/her?

5) You want to buy new clothes for a school party/work party. What information will you need before you decide what to buy?

6) Also ask the family to share examples of choices they have made when they have needed more information.

- Discuss the following questions: "Who helps you when you need information?", "Where do you go to get the information you need when you are making choices?" , and "What happens if you don't get the information you need?"

Review and Reflect

- How does knowing what information is needed help you in making choices?

Activity 3: Supporting Others' Choices

Introduction

The purpose of this activity is for the family to understand how it can support members' choice-making. Having a family means having a built-in support system for every aspect of living. Choice-making is just one of many areas that can be supported by other family members. The purpose of this activity is to identify choices that family members are making, and ways that family members can provide support for each other.

Materials Needed

Paper and pencils or pens; a flipchart can also be used.

Preparation for Facilitator

None.

Preparation for Family

The family should come with examples of choices they would like to make in the future. As in Activity 1, family members can prepare for this activity by making a list or thinking of two choices they would like to make, such as who to have as friends, what classes to take, or how to spend leisure time.

It is important for families to see that providing support in the manner it is asked for is a sign of respect for another person's judgment, abilities, and autonomy.

Instructional Procedure

- Explain that this activity is meant to help identify how family members can support each other's choice-making.
- Ask for someone to start. On a piece of paper or flipchart, write down the choice the family member hopes to make. Down the side of the page write the other family members' names. Ask the person what each family member could do to support their choice-making. Document these ideas next to each person's name.
- Ask the other family members if they feel they can support the choice-making in the ways mentioned, and if they have any other ideas on how they can help support the choice.
- Repeat the same steps with whomever wishes to participate.
- Discuss the following: "How do you feel when other family members do something to support your choices?", "How do you feel when family members do not do anything to support your choices?" , and "Can family members do too much to support your choices?".

Review and Reflect

- How is self-determination affected when other family members provide support?

Activity 4: Generating Alternatives

Introduction

Knowing available options is an important part of making choices. In this activity, family members have the opportunity to come up with ideas about their options for a variety of situations. Hearing how other family members generate alternatives can be insightful in understanding how they make choices. This activity will help family members generate several alternatives when provided with hypothetical choice-making opportunities.

Materials Needed

Paper, pen or pencil; note cards with choice-making scenarios written on them (see list on next page).

Preparation for Facilitator

Bring note cards with scenarios written on them.

Preparation for Family

Bring examples of choices they would like to make in the future.

As people face obstacles and problems, they often tend to feel they have a lack of options. Brainstorming about alternatives can help families see that they may have more choices than they have previously believed.

Instructional Procedure

- Explain that this activity is meant to help the family get a better look at how they generate alternatives when they are making a choice.
- One family member will pick a choice-making scenario card. One family member will read the card and make sure everyone understands it. Possible scenarios are:

  1) How many different things can you think of to do with two free hours on Saturday afternoon?

  2) You just won $1,000 in a local contest. What are some things you can do with the money?

  3) You want to do something special for your Mom or Dad on Mother's Day/Father's Day. What are some different things you can choose from?

  4) Your family wants to do something together on Sunday afternoon. What are some different ideas to choose from?

  5) You want to earn some extra money for a vacation that is coming up in a few months. What are some different ways that you could get the extra money you need?
- Each family member will give a possible choice for the scenario. Write all the alternatives generated without evaluating them.
- Repeat the above steps as often as the family desires.
- Discuss the following: "What did you like about the activity, and what didn't you like about the activity?" "How did you go about thinking up alternatives?" "Did everyone in the family think about alternatives in the same way?" "What are some situations when you need to think up alternatives as you make choices in your lives?" "Once you think up several choices how do you decide which is the best one for you? Do your choices usually work out?"

Review and Reflect

- How is self-determination affected by being able to generate alternatives?

Preparation for Next Module

Among the other skills needed for successful choice-making is the skill or ability to persevere when things don't work out well, which is the topic of the next module.

- Ask family members to think of instances in their lives when choices they made did work out and did not work out.

8 Persevering in Choice-Making

Introduction

The adage "If at first you don't succeed, try, try again" is especially well suited to choice-making. Making choices can be difficult, and building skills to make effective choices requires willingness to persevere. In choice-making, as with anything new or different, it is important to be willing to try several times before experiencing success. Often, we learn more from our "bad" choices and their consequences than from our "good" choices. Looking at what went wrong and wny can help us make better choices in the future. Asking ourselves, "Did I look at all the alternatives?", "Was the consequence of that choice unforeseen?", and "Did I implement the choice appropriately?" can help us focus on what we can do to improve our ability to make successful choices in the future.

Learning from the experiences of others can also encourage perseverance in choice-making. Family members model for each other how to make choices and learn from experience. Reflecting on reactions to successful and unsuccessful choice-making experiences of family members is one way the family can support each other in making choices. Also, knowing that other people care about and support each other even though a family member may make an unsuccessful choice gives all family members the feeling that they can survive setbacks and failures and keep making choices. For children and adolescents, the family is a natural support system where they can make choices and live with the consequences while being loved and supported by parents and other family members.

Overview of the Module

This module is designed to help family members support each other in practicing choice-making and in persevering when choices don't work out. The first two activities give the family the opportunity to share experiences with choices that did and did not work out for them and to discuss how they can support each other when making choices. The third activity is designed to stimulate discussion about how family members can give each other support in choice-making and about how much support each family member wants and needs. This module is designed to be completed in one session of approximately two hours.

Module Goals

- *The family will discuss how to persevere when choice-making is difficult.*

Module Objectives

- *Family members will identify components of choices that have worked out for them.*
- *Family members will identify components of choices that didn't work out for them.*
- *The family will discuss how it can support each family member's choice-making and ways to improve that support.*

Module Activities

- *Choices That Have Worked*
- *Choices That Haven't Worked*
- *Supporting Choice-Making*

Activity Plans

Activity 1: Choices That Have Worked

Introduction

They say experience is the best teacher. The purpose of this activity is to share experiences the family has had making choices that did work out successfully. Sharing these stories can be a positive and affirming way for family members to learn from each other. It is also a wonderful way to focus on the positive things that family members have accomplished.

Materials Needed

Paper, pen, and pencils.

Preparation for Facilitator

None.

Preparation for Family

Family members will think of instances in their lives when choices they made did work out.

Instructional Procedure

- Introduce this module and activity by talking about the need to persevere in choice-making (base your comments on the material in the Introduction to this module on page 87).
- Explain that this activity is meant to help family members recognize the things that have contributed to their past successes in choice-making.
- Ask if someone would like to start (if no one volunteers, ask a parent to start). The family member who begins will describe an experience when he/she made a choice that worked out successfully. Ask the person to describe how the choice was made, the outcome of the choice, and how the person felt after making the choice.
- Ask other family members if they have any ideas of what the person did that helped him/her be successful.
- Each family member who would like to participate will share an experience, and the group will discuss what the person did that helped the choice be successful.
- Discuss the following: "What did you learn from your experiences with choices that worked out well?", "How did your family

This module is designed to help family members support each other in practicing choice-making and in persevering when choices don't work out.

members support your choices?", "How did being successful encourage you to persevere when making other choices?", and "How do you think you can use what you have learned in the future?"

Review and Reflect

- What effect does reflecting on successful choices have on self-determination?

Activity 2: Choices That Haven't Worked

Introduction

The purpose of this activity is to share experiences the family has had making choices that did not work out. Sometimes we learn more from experiences that did not work out than from those that did. Sharing stories of choices that did not work out as planned is one way for family members to learn from each other and talk about what they could have done differently.

Materials Needed

Paper, pen, and pencils.

Preparation for Facilitator

None.

Preparation for Family

Family members will think of instances in their lives when choices they made did not work out.

Instructional Procedure

- Explain that this activity is meant to help family members understand that everyone has had experiences making choices that did not work out the way they wanted them to.
- Ask if someone would like to start (if no one volunteers, ask a parent to start). The family member who begins will describe an experience when he/she made a choice that didn't work out. Ask the person to describe how the choice was made, the outcome of the choice, how the person felt making the choice, and what could be done differently if the person could do it again. Write down the information about the unsuccessful choice. This information will be used in Activity 3.
- Ask other family members if they have any ideas of what the person could have done to experience a more desirable outcome.

Sometimes, families and others try to protect young people with disabilities from taking risks, making mistakes, and learning for themselves what works and what doesn't. For young people to grow in confidence and the ability to express self-determination, they must have opportunities to try, fail, and try again.

- Each family member who would like to participate will share an experience and other family members can generate ideas for creating a more desirable outcome.

- Discuss the following: "What do you do currently if a choice you make doesn't work out?", "What did you learn for experiences where a choice you made didn't work out?", "How can you change what didn't work next time?", and "How was this experience different from a successful experience you have had?"

Review and Reflect

- What is the importance for self-determination of being able to learn from choices that did not work out?

Activity 3: Supporting Choice-Making

Introduction

When making choices, it is helpful to have a safe environment with people who will support you whether or not your choices work out. For children and adolescents, the home should be such a place. Support can be provided in many ways. The most basic is an atmosphere of love and acceptance for all family members no matter what their choices or the consequences of those choices. Affirming the worth of each individual provides motivation to take risks. Some family members will need other types of support, such as encouragement to try new things or ideas for where to get information to make informed choices. Some family members may need coaching on specific steps of choice-making, and others may need more opportunities to practice. The purpose of this activity is for family members to discuss how they currently provide each other with support and whether that needs to change.

When making choices, it is helpful to have a safe environment with people who will support you whether or not your choices work out. For children and adolescents, the home should be such a place.

Materials Needed

Paper, pens, and pencils; information about choices that did not work out (from Activity 2).

Preparation for Facilitator

None.

Preparation for Family

None.

Instructional Procedure

- Explain that the activity is meant to help the family identify what help or support is needed when making a choice.

- Using the information recorded in Activity 2, go over each choice that didn't work out. Ask the family member who made the choice the following questions:

  1) What support did you receive from other family members when you made that choice?

  2) What support did you receive from other family members when you suffered the consequences of the choice?

  3) Is this support different from the support you receive when the choices you make are successful?

  4) Would you have liked to have had different support? In what way?

- After the choice-maker has answered the questions, repeat the questions for each family member, asking what support each gave this person in making that choice, etc.
- Repeat the above steps for each family member who shared a choice in Activity 2.
- For each family member, discuss whether the type and amount of support they receive should be changed. If yes, develop a plan to change the support provided.

Review and Reflect

- How is making choices affected by the support you have?
- Does everyone in the family receive the same support when they are making choices? Why or why not?

Preparation for Next Module

- If the family did not do Activity 5 from Module 4, ask family members to identify and write down some individual goals they would like to implement in their lives. They should think about goals in various areas of life, such as home, recreation, school, work, and health or health care. The goals should be manageable and able to be accomplished.

Continuing to make choices even when every choice isn't successful is the key to realizing one's vision, the topic of the next module.

9 Realizing Your Vision

Introduction

Realizing your vision means an individual engages in certain behaviors to attain a goal he/she has chosen. *Self-regulation* and *self-management* are other terms that have been used to describe the behaviors that occur when an individual makes choices that enable the individual to achieve goals and realize his/her vision for an aspect of life.

A key to realizing one's vision is the transformation from external to internal control. This occurs naturally as children mature when primary caregivers exert less external control over children's behavior and place more responsibility on the children to control their own behavior. To generate the desire for self-regulation, individuals must realize that they are creative agents, responsible for and capable of self-determination, and they must appreciate and understand their capabilities for reaching their goals.

However, for some individuals the transfer from external to internal control does not happen. The basic skills of realizing one's vision may be absent or too weak, and the individual may be excessively influenced by events in the environment. As a result, these individuals may view others as being in charge and themselves as having minimal influence over or personal responsibility for their behavior. Parents or other caregivers in their environment may also not have ceded control over aspects of the individual's behavior at the point when this normally should occur. The caregivers may have felt that the individual was not capable of assuming control or that they must protect the individual from the consequences of making bad choices. Disruptive behaviors may then occur as a means by which the individual can exert some control or because the individual has not been taught more appropriate ways of behaving in provocative situations.

Overview of the Module

The purpose of this module is to share information about how individuals can change their behavior in order to work toward and achieve goals they set. The activities in the module are designed to help families implement goals or choices to realize visions, enhance effectiveness of behaviors that help in reaching goals, and identify rewards family members would like to receive. This module is designed to be completed in one session of approximately two hours.

Module Goals

- *Family members will identify and work toward individual goals.*
- *Family members will identify what they do when they reach or fail to reach goals.*

Module Objectives

- *Family members will identify individual goals they would like to work toward and steps they will take to reach them.*
- *Family members will keep charts, checklists, or journals on progress toward their goals.*
- *Family members will identify past individual goals they were successful in reaching.*
- *Family members will identify behaviors that would be useful in reaching their goals and develop plans to incorporate the behaviors into their lives.*
- *Family members will identify rewards they give themselves, receive from others, or would like to receive from others.*

Module Activities

- *Goal Setting*
- *Learning from Successes*
- *Goal-Directed Behavior*
- *Recording Progress*
- *Identifying Rewards*

Activity Plans

Activity 1: Goal Setting

Introduction

In this activity, each family member will have an opportunity to discuss goals he/she wants to implement as an individual and/or as a family. This structured format may be unnecessary for some, but for other families it is a positive way to collaborate in goal-setting. Self-determination skills require cooperation and support. This activity is designed to provide that support.

Materials Needed

Paper, pen, flipchart, board to document the discussion; future map from the focus person's Personal Futures Plan (Module 2); blank future maps from Module 2; lists of personal and family goals from Activity 6 of Module 4.

Preparation for Facilitator

None.

Preparation for Family

If family members did not complete Activity 6 in Module 4, they will at this time identify and write down goal(s) they would like to implement in their lives. They should think about developing goals in different areas of their lives, such as home, recreation, school, work, and health or health care. The goals identified should be manageable and attainable.

Instructional Procedure

- Introduce this module and activity by defining what it means to realize one's vision (base your description on the information in the Introduction to this module on page 93).
- Review the future map developed for the focus person in Module 2. Check to see if there are any changes. Have any goals been accomplished? Are there areas of life where the young person has no goals? Do goals need to be added?
- Review the goals other family members listed in Activity 6 of Module 4 or in preparation for this session. Fill out future maps for each family member.
- In a round-robin fashion starting with the youth/young adult with a disability, ask: "What goal would you like to start working on now and what are three steps you can take toward that goal?" Record goals and steps for each family member.

The purpose of this module is to share information about behavior: how a person's behavior affects others, how an individual reacts to others' behaviors, and how to enhance useful or productive behavior.

- Ask if there is a joint family goal they would like to implement. If so, plan a strategy to implement the goal.

Review and Reflect

- How did this activity help your ability to set goals as an individual? As a family?
- How did this activity increase your understanding of self-determination?

Activity 2: Learning from Successes

Introduction

Reviewing successes is not only a good way to identify things that worked in the past, it feels great! Talking about things that went well and worked out is a wonderful way to examine what behaviors and strategies are useful and successful. Knowing what works is important for self-determination and making choices; without knowing what is effective, it is hard to experience good results. The purpose of this activity is for family members to identify past goals they reached, and discuss how they can use the successful behaviors of the past to increase the likelihood of attaining future goals.

Materials Needed

Paper, pen, flipchart to document the discussion.

Preparation for Facilitator

None.

Preparation for Family

None.

Instructional Procedure

- Explain that realizing one's vision involves reaching specific goals, and that reviewing past successes can help individuals determine what works for them when trying to reach goals.
- Have each family member identify a past goal that he/she was successful in reaching, and how the behaviors that were successful in reaching a goal could be applied in future situations. Record responses on the flipchart and discuss. Questions to ask include:

  1) How did you identify the goal and then plan to reach the goal?

  2) How were you supported by your family and friends to reach your goal?

It is especially important in this activity that the youth/young adult with a disability be able to identify a goal he/she successfully reached.

3) What supports would you need to incorporate the successful behaviors in your life and decrease the unsuccessful behaviors?

Review and Reflect

- How does recognizing past achievements help increase how self-determined you feel?
- How can your family continue to learn from family members' successes?

Activity 3: Goal-Directed Behavior

Introduction

The family members will identify behaviors that they feel would be useful in order for each of them to reach the goals they set individually and/or as a family in Activity 1. They will discuss means to incorporate these behaviors more solidly into their lives.

Materials Needed

Paper, pen, flipchart to document discussion; record of goals identified by family members in Activity 1.

Preparation for Facilitator

None.

Preparation for Family

None.

Instructional Procedure

- Beginning with the youth/young adult with a disability, each family member will identify a behavior he/she feels would be useful in reaching the goal identified in Activity 1.
- Document and discuss the behaviors the family members identified as useful or productive in order to reach their goals and how they could more solidly incorporate the behavior into their lives. The following questions can be used as a tool for the discussion:

1) What behavior(s) do you feel would be useful or productive?

2) Why do you feel this behavior is useful or productive in helping you reach the goal you set?

3) How could you incorporate this behavior into your life?

4) What supports would you need to incorporate this behavior into your life?

For some people it is helpful to identify and then either write down or discuss goals. Taking this formal step of naming goals can help individuals focus on achieving what they really want for their lives.

5) How could you record the progress and effectiveness in which you are incorporating this behavior into your life?

- If the family has identified a joint goal, identify a behavior that the family as a whole could incorporate into its life in order to help it reach that goal. Document and discuss this behavior as above.

Review and Reflect

- How will incorporating this behavior into your life help you be more self-determined?
- How will the supports you use to incorporate this behavior be useful in being more self-determined?

Activity 4: Recording Progress Toward a Goal

Introduction

Journaling or keeping charts of progress is a concrete way to monitor movement toward a goal. It is also a good way to encourage patience and persistence. Often when working toward a goal it is easy to let things slide - then gradually forget about the goal altogether! A journal or chart gives good information and provides the impetus to continue striving for a goal in spite of setbacks. The purpose of this activity is for the family to develop means to support and monitor progress in reaching goals. The family members will use checklists, charts, or journals to monitor their progress toward reaching their goals or the thing in their lives that they would like to change.

Materials Needed

Paper, pen, journal, flipchart, board to document the discussion; record of goals and strategies developed in Activity 1.

Preparation for Facilitator

None.

Preparation for Family

None.

Instructional Procedure

- Using a family or individual goal from Activity 1, discuss how the individual and/or family can monitor progress towards the goal using a chart, journal, etc. Set up a means to monitor progress and ways to document progress achieved. Questions to consider in setting a monitoring system are:

1) What do you need to record?

Guiding family members through the goal-setting process assists them in learning to reflect on where they're going and why, an essential step in the exercise of self-determination.

2) How do you need to record the information?

3) How would you like to use this information so you can see the progress that is being made toward the goal?

4) How would you like to monitor or reinforce the outcomes?

5) What types of support do you need for implementing these activities into your life?

- Ask the family to keep the following questions in mind while they are working on recording progress towards a goal: "What is helpful for you to stay focused on a goal?" and "What things distract from a goal?"

Review and Reflect

- How will monitoring your progress help increase your self-determination?

Activity 5: Identifying Rewards

Introduction

Realizing one's vision is not an easy task. Along the way, the typical individual makes many wrong turns and experiences considerable frustration. Why do people persist, even in the face of considerable odds? For most, one key is breaking down the vision into a series of short-term goals and receiving rewards as the more immediate goals are attained. These rewards - which may come from one's self or from others - are the motivators that keep one going in the face of adversity. Individuals must be careful in determining what is rewarding to another person, however. What was once an effective reward may no longer serve this purpose, and what one person finds rewarding may not be a significant reward for another.

Materials Needed

Paper, pen, flipchart to document discussion.

Preparation for Facilitator

Be prepared to provide examples of rewards.

How can all family members, including the member with a disability, monitor their progress toward their goals?

Preparation for Family

None.

Instructional Procedure

- Introduce this activity by explaining that one way that people keep going with the hard work of realizing their vision is through setting small goals and receiving small rewards on the way to the big goal.

- Ask family to define a reward. Record their responses on the flipchart.
- Ask each family member to write down on a sheet of paper his/her answers to the following three questions (each person should write his/her own answers without discussing them with others; let the family know that what they write will be shared with the group in a few minutes):

  1) What are some examples of rewards you give yourself?

  2) What are some examples of rewards others give you?

  2) What are some rewards you would like to receive?

  3) What are examples of "rewards" you wish you did not receive?

- Collect the lists and share information you have listed without identifying who wrote it. Ask the family members to guess who wrote each piece of information. Discuss the fact that everyone doesn't necessarily desire the same rewards, that the rewards a person wants will change over time, and that it's important to know what is rewarding to each individual at a given time in life.
- Discuss how family members can build in rewards for achieving small goals on the way to realizing their visions. Use the following questions to facilitate discussion:

  1) What rewards would you like incorporated into your life?

  2) How can you assure that rewards you want are incorporated into your life?

- Have each family member identify a reward or system of rewards that they will use when they have attained the goal they set in Activity 1 and/or have made a certain amount of progress towards attaining that goal.

Review and Reflect

- How can self-determination be enhanced by knowing what rewards are effective?

Preparation for Next Module

- Prepare the problem situation scenario note cards (see pages 102-103).
- Ask family members to bring examples of problem-solving that were successful and ones that were unsuccessful.
- Copy the handout, *Six Steps of Problem-Solving* (pages 106-107 of Module 10) for each participant; to be distributed during next session.

Everyone deserves to feel that they are a success. Make sure every family member identifies at least one goal - large or small - that they've attained.

10 Solving Problems

Introduction

Problem-solving is a process or technique a person uses to "discover" a solution to a problem. Problems can be solved by using various approaches, some more successful than others. There are specific steps that have been shown to be very effective in solving problems, and young people with disabilities can benefit by learning and applying them to situations that they encounter in everyday life. The steps, together with the belief that one has the ability to successfully cope with problems, dramatically increases the likelihood that a young person will eventually arrive at acceptable solutions.

The six steps to successful problem-solving presented here range from initial identification of the problem and desired outcomes to developing, evaluating, selecting, and implementing a solution to remove the obstacle encountered. The process, however, does not stop here for few individuals are successful 100% of the time with the first solutions they develop and implement. Rather, problem-solving is a process in which ideas are developed and tried out, and their success in eliminating the problem evaluated. The use of problem-solving strategies with proven effectiveness will, however, make finding acceptable solutions an easier and less stressful task.

Problem-solving is important for self-determination because everyone faces obstacles in their lives and must overcome them to realize personal visions and goals. Being able to overcome these obstacles in a positive manner will result in individuals continuing to exert control over their lives and make their own decisions.

Overview of the Module

The purpose of this module is to present the six steps of problem-solving and provide the opportunity for family members to practice these steps. In addition, family members will share successful and unsuccessful problem-solving experiences they have had in the past and discuss how they can learn from these experiences and be more successful problem-solvers in the future. This module is designed to be completed in one session of approximately two hours.

Module Goals

- *The family will learn about and practice six steps of problem-solving.*
- *The family will facilitate problem-solving by learning from past problem-solving experiences.*

Module Objectives

- *The family will receive information about the six steps of problem-solving.*
- *The family will practice the steps of problem-solving through the use of problem situation scenarios.*
- *The family will share experiences of successful problem-solving and discuss why they were successful.*
- *The family will share problem-solving experiences that were not successful and discuss why.*

Module Activities

- *Six Steps of Problem-Solving*
- *Reviewing Successful Problem-Solving Experiences*
- *Reviewing Unsuccessful Problem Solving Experiences*

Activity Plans

Activity 1: Six Steps of Problem-Solving

Introduction

Problem-solving can be defined as the process or technique by which one attempts to discover a solution to a problem. In this activity, the six steps of problem-solving will be presented. These steps were designed by researchers as a guideline for successful problem-solving experiences. The family will practice using the six steps of problem-solving by reading and responding to problem situation scenarios.

Materials Needed

Flipchart and pens; copies of, *Six Steps of Problem-Solving* (see pages 106-107 in the Supplemental Information at the end of this module) to give to each family member; copies of the problem situation scenarios on note cards.

Preparation for Facilitator

Prepare the problem situation scenario note cards and make copies of *Six Steps of Problem-Solving* (see pages 106-107 in the Supplemental Information at the end of this module) for each family member.

Preparation for Family

None.

Instructional Procedure

- Introduce this module and activity by defining problem-solving and its role in self-determination (base your comments on the Introduction to this module on page 101). Explain that in this activity the family will look at six steps of problem-solving.
- Pass out a copy of *Six Steps of Problem-Solving* (see pages 106-107 in the Supplemental Information at the end of this module) to each family member and read through the steps out loud and discuss so that each family member understands each step.
- Practice the steps of problem-solving by using the scenario cards. Ask each participant, in turn, to pick a scenario card and read the situation on the card. Have each person tell how he/she would solve the problem using the steps of problem-solving. Ask the other family members if all the steps were included and if they have anything to add. Repeat for the each family member. The scenarios are:

The purpose of this module is to present the six steps of problem-solving and provide the opportunity to practice them.

1) You go to school/work in the morning and you realize you've forgotten a very important file at home. What do you do?

2) You have the chance to go on a trip with friends to one of your favorite places, but the trip conflicts with a prior family commitment. You really want to take the trip. What do you do?

3) Because of a doctor's appointment you miss practice for the athletic team. Your coach calls you that night and tells you that you are off the team. What do you do?

4) You, a parent, have committed to doing two things after school with two different siblings, and both things are important and are happening at the same time. What do you do?

5) Your close friend calls and says she is very upset about something and needs to talk to someone about it. You are just heading out the door with your family to the school talent show. What do you do?

6) Your parent or significant adult is out of town and you are supposed to watch your younger sibling. You get invited to a party that you really want to go to. What do you do?

Review and Reflect

- Are the six steps of problem-solving different from how you normally would solve a problem? If so, how?
- In what ways could the six steps of problem-solving enhance self-determination?

Activity 2: Reviewing Successful Problem-Solving Experiences

Introduction

The purpose of this activity is to look at family members' experiences with successful problem-solving. Knowing what contributed to successful problem-solving in the past facilitates successful future problem-solving.

Materials Needed

Flipchart and pens.

Preparation for Facilitator

None.

Preparation for Family

Family members will bring examples of successful problem-solving.

Many youth with disabilities need help learning problem-solving skills. One way they can learn is from other family members.

Instructional Procedure

- Explain that one way to learn how to problem-solve is to look at how an individual has successfully done it in the past. Ask a family member to describe a successful experience he/she has had with problem-solving, and to identify the steps used to solve the problem. Questions to facilitate discussion are:

  1) What was the first thing you thought of when you encountered the problem?

  2) What steps did you use to solve it?

  3) Why was your problem-solving experience a success?

- Document the information on the flipchart. (Keep in mind that family members may have used steps other than the ones identified on the list, and all the steps that they used should be documented on the flipchart). Encourage other family member to share their experiences and document in the same way.

- Review what has been written, discussing the following:

  1) Were the steps you used the same as the ones we talked about in the first activity? Why or why not?

  2) Would you do anything differently now that you know the problem-solving steps?

Review and Reflect

- How can reflecting on successful problem-solving experiences enhance self-determination?

Activity 3: Reviewing Unsuccessful Problem-Solving Experiences

Introduction

Some problem-solving methods result in unsuccessful experiences. Learning from mistakes is also helpful, sometimes more so than learning from successful experiences. The purpose of this activity is for family members to identify experiences in problem-solving that did not work out, the steps that were taken during these experiences, and how the steps in problem-solving might be improved.

Sometimes problem-solving leads to unsuccessful outcomes, which lead to further problem-solving.

Materials Needed

Flipchart and pens.

Preparation for Family

Family members will bring their own examples of problem-solving that did not work out.

Preparation for Facilitator

None.

Instructional Procedure

- Explain that this activity is meant to help family members identify when problem-solving isn't working, and why it isn't working. (You can also explain that this activity is very much like the previous one except instead of identifying successful problem-solving the family will identify problem-solving that didn't work).
- Ask a family member to describe an experience they have had when their problem-solving was not effective. They will identify the steps they took when they were trying to solve the problem. Document the problem and the steps that were taken on the flipchart. Be prepared to share an experience of your own to generate discussion if the family does not have their own experiences to share. Questions to facilitate discussion are:

  1) What steps did you take when you were trying to solve the problem?

  2) Which of your steps were effective?

  3) Which of your steps were not effective?

  4) Why were these steps ineffective?

  5) What did you do when you realized your problem-solving was not going well?
- Ask family members to give suggestions of what might have worked better.

Review and Reflect

- How does reflecting on unsuccessful problem-solving experiences enhance self-determination?

Preparation for Next Module

- Ask family members to come to the next session with examples of situations that involve conflict within the home, and examples of conflict outside the home.
- Make copies of the handout, *Steps of Negotiation* (see page 116 in the Supplemental Information section of Module 11) to be distributed in the next session.
- On note cards, write out each role play scenario for Activity 4 of Module 11 (see page 114-115 of Module 11).

The six steps of problem-solving are one set of tools for self-determination; another is the conflict resolution strategies found in the next module.

Supplemental Information

Six Steps of Problem-Solving

- **Step 1: Identify the Problem**
  Most problematic situations we encounter appear to be "messy". In other words, the situation may appear so broad or vague that you can't always tell exactly what the problem is. For effective problem-solving, the problem solver must avoid using terms that are too vague or ambiguous to be meaningful. You must know specifically what the problem is. Saying that "Dad gets on my case" is not specific enough. Saying that "Dad yells at me when he thinks I haven't done my chores" is specific.

- **Step 2: Identify the Desired Outcome**
  Once you know exactly what the problem is, you need to know what you want to have happen. In other words, you have to identify what you want the outcome to be or set a goal. Setting a goal isn't always easy. Sometimes we set goals that are unrealistic and impossible to attain. It is very important to really examine a problem, and identify goals that can realistically be reached.

- **Step 3: Generating Alternatives**
  The major task during this stage is to generate possible solutions appropriate to the situation - this can be called brainstorming. Four things to remember about brainstorming are:

  1. Do not criticize ideas (get them all down and eliminate some later).

  2. The wilder the idea the better (it can be modified later).

  3. Quantity is wanted (the greater the number of ideas, the greater the likelihood of useful ideas).

  4. Work toward combination and improvement (try to make suggestions into better suggestions by combining them).

  In other words, alone or with a parent, brother, sister, or friend, think about all the solutions that might solve the problem. Write down the solutions, even if they seem silly.

- **Step 4: Evaluate Alternatives**
  In this step, you weigh the various alternatives, determining the consequences or outcomes of each possible solution. You speculate about the long-term and short-term outcomes, and see how these outcomes fit with your individual value system and your family's value system.

- **Step 5: Select Alternative (Decision Making)**
  In this step, weigh the various alternatives, each against all others. Consider the value of each alternative, and eliminate options that are not feasible solutions. Some alternatives will be easy to cross off the list, but others will require careful consideration. At the end of this process you will choose one solution to try.

- **Step 6: Evaluate Results**
  After the problem has been identified, possible solutions generated, solutions evaluated, and a solution chosen and tried, the final step is to see if the solution that was tried was an effective one. This step is very important.

Parents can assist children in using the steps for problem-solving. Being clear on what the problem is can be difficult for adults, let alone for adolescents. Parents and other family members can help young people both in the process of applying the steps to their own problems and by modeling the steps when addressing the problems we all face.

The six steps are adapted from the following materials:

T.J. D'Zurilla and M.R. Goldfried (1971). Problem-solving and behavior modification. *Journal of Abnormal Psychology, 78*, 107-126.

DeMerit, K.S., Halter, P.L., Jauron, G., Jirovetz, L., & Kruger, M. (1988). *Charting a bold course*. Green Bay, WI: Brown County Association for Retarded Citizens.

Elliott, S. N. & Gresham, F.M. (1991). *Social skills intervention guide*. Circle Pines, MN: American Guidance Service.

Nezu, C.M. & Nezu, A.M. (1991). Assertiveness and problem-solving training for mildly mentally retarded persons with dual diagnoses. *Research in Developmental Disabilities, 12*, 371-386.

11 Resolving Conflicts

Introduction

Everyone has conflict in their lives, whatever their level of self-determination. *Conflict* refers to problems or friction between two or more sides. Conflicts range from minor annoyances about the best way to do a simple task to major disagreements about lifestyles. While we can not escape conflict in our lives, we can minimize its effects by learning how to resolve it in an appropriate manner.

The method of conflict resolution described in this module is *negotiation*. Negotiation involves two or more people reaching an agreement together where all parties are satisfied with the decision reached. It is carried out in a manner that allows the parties negotiating to get some of their needs met, to have their needs heard because they communicate, and to have the possibility for future interaction through this communication. Negotiation does not involve one party getting his/her way through overpowering the other parties or telling them what to do.

Compromise is an important part of negotiation. Compromise is defined as two or more people mutually giving away part of what they currently have or want in order to agree. Both sides have or want something that is incompatible with what the other side has or wants. In order for both sides to come away from the negotiation satisfied, they will each have to give up something. It may take awhile for both sides to agree on a solution with which they are satisfied. Compromise mirrors the choice-making and problem-solving processes; alternative solutions are generated and evaluated, and the one that best fits the needs of both parties and is feasible is selected.

Overview of the Module

The purpose of this module is to identify the current methods family members use to resolve conflicts. The steps of negotiation will be presented to family members, and they will be provided opportunities to practice these steps. The skills required for successful negotiation are based upon those discussed in previous modules, particularly the choice-making and problem-solving modules. This module is designed to be completed in one session of approximately two hours.

Module Goals

- *The family will work together to identify its style/process of conflict resolution.*
- *The family will integrate negotiation into its style/ process of conflict resolution.*

Module Objectives

- *The family will identify conflict resolution methods that members use at home.*
- *The family will identify situations outside the home in which family members used conflict resolution methods.*
- *The family will learn about the steps of negotiation.*
- *The family will practice the steps of negotiation.*

Module Activities

- *Current Conflict Resolution Methods Used Within the Home*
- *Current Conflict Resolution Methods Used Outside the Home*
- *Defining the Steps of Negotiation*
- *Role Plays of Negotiation Skills*

Activity Plans

Activity 1: Current Conflict Resolution Methods Used Within the Home

Introduction

In the previous module, we talked about problem-solving situations an individual may face. In this module, we discuss problem-solving experiences that are done in collaboration with other people in order to resolve conflicts. The purpose of this activity is for family members to identify situations that occur within their home that involve conflict, and to identify how the family generally works through these situations.

Materials Needed

Flipchart and markers.

Preparation for Facilitator

None.

Preparation for Family

Family members will come to the session with examples of situations that involve conflict within the home.

Instructional Procedure

- Introduce this module and activity by defining conflict and describing methods of resolving it (base your comments on the Introduction to the module on page 109). Explain that this activity is meant to help the family recognize the conflict resolution methods they currently use within the family.

- Ask family members to give examples of situations that involve conflict within their family. List these on the flipchart.

- Ask the family to look at each example, one at a time, and describe how they resolve the conflict. Be sure to offer each family member a chance to give his/her view. (This discussion could lead to conflict if family members do not agree on what happens in conflict situations. You can point this out as an example of the kind of conflict that occurs in families). Document on the flipchart the various descriptions of the family's conflict resolution methods. Use the following questions to facilitate discussion:

1) What situations in your family involve conflict?

2) How does your family resolve these conflicts?

The purpose of this module is to identify the current methods family members use to resolve conflicts, and provide additional tools.

3) How often does your family negotiate?

4) Who is a good negotiator in your family? Why?

Review and Reflect

- What do you like about the way your family resolves conflicts?
- What would you change about the way your family resolves conflicts?

Activity 2: Current Conflict Resolution Methods Used Outside the Home

Introduction

Of course, conflicts in which family members are involved are not limited to the home. Each family member is involved in different settings such as work and school where conflicts may arise with coworkers, bosses, teachers, and friends. The purpose of this activity is to identify situations outside of the home in which family members have conflicts, and what methods they use in those situations to resolve conflict.

Materials Needed

Flipchart and markers.

Preparation for Facilitator

None.

Preparation for Family

The family will come to the session with examples of situations outside of the home that involve conflict.

Instructional Procedure

- Explain to the family members that this activity is meant to help them identify situations with others outside of their family that involve conflicts and the methods they use to resolve them.
- Ask the family members to give examples of situations that involve conflict outside of the home (at school, at work, in the community, etc.). List these examples on the flipchart.
- Look at each example one at a time, and have the family describe how they resolve their conflicts in these situations. Be sure to offer each family member a chance to give their views. Questions to facilitate discussion:

1) How do you resolve these conflicts?

Many people are uncomfortable with conflict and lack the skills to resolve situations in a respectful manner. Be aware of the comfort level of the family during these exercises and keep them focused on resolving conflicts productively.

2) How do you feel when you are resolving a conflict?

3) What conflict resolution methods have been successful for you?

4) What conflict resolution methods have not been successful for you?

5) Do you resolve conflicts differently at home than at work, school, etc.? Why or why not?

Review and Reflect

- How does being able to resolve conflicts to your satisfaction enhance self-determination?

Activity 3: Defining the Steps of Negotiation

Introduction

The purpose of this activity is for the family to become familiar with the six steps of negotiation and to apply the steps to situations that the family has encountered. These steps are particularly helpful to families who have had some difficulties in negotiation and conflict resolution, either inside or outside their home. The steps can be used in conjunction with other successful conflict resolution strategies that the family may have previously identified.

Materials Needed

Flipchart and pens; copies of *Steps of Negotiation* (see page 116 in the Supplemental Information at the end of this module) for each family member; lists of situations that involve conflict from Activities 1 and 2.

Preparation for Facilitator

Make copies of *Steps of Negotiation* (see page 116 in the Supplemental Information at the end of this module) for each person.

Preparation for Family

None.

The steps described here are not the only steps to successful negotiation. The family may have their own set of steps to share.

Instructional Procedure

- Explain that in this activity the family will look in detail at one method of resolving conflict: *negotiation*. Define negotiation for the family based on the definition in the Introduction to this module on page 109. Explain that this activity is meant to help the family understand the process of negotiation and to apply that process to situations they encounter every day. Emphasize that the steps described here are not the only steps to successful negotiation, and that family members may have steps of their own they would like to share.

- Pass out copies of *Steps of Negotiation* (see Supplemental Information on page 116 at the end of this module), one to each family member. Read the six steps out loud, writing the key words of each step on the flipchart.
- Discuss each step. Ask the family, "What could happen if a person did not do this step when they are negotiating?" and "What steps in this process do you sometimes leave out? Why?" Document this information on the flipchart, encouraging all family members to participate in the discussion.
- Ask family members to remember the situations that they mentioned in the previous activity, which involved conflicts. Guide them in applying the six steps of negotiation to the situations. Document these responses on the flipchart.

Review and Reflect

- How can using the steps of negotiation enhance a person's self-determination?

Activity 4: Role Play of Negotiation Skills

Introduction

In the previous activity, the steps of negotiation were presented to the family members, and they had the opportunity to apply those steps to situations in their lives. However, since negotiating can sometimes be tricky, particularly in emotionally charged situations, more practice may be needed. The purpose of this activity is to provide family members with the opportunity to practice negotiation skills through the use of role plays.

Materials Needed

Role play scenarios on note cards (see pages 114-15); copies of *Steps of Negotiation* (see page 116 in the Supplemental Information at the end of this module) for each family member; lists of situations that involve conflict from Activities 1 and 2.

Preparation for Facilitator

Make copies of *Steps of Negotiation* (see page 116 in the Supplemental Information at the end of this module) for each person; make notecards with the role play scenarios listed below.

Preparation for Family

None.

It may be desirable to establish ground rules for role-playing, such as no abusive language, no physical control, no shouting.

Instructional Procedure

- Explain that this activity is meant to provide family members with the opportunity to practice negotiation skills through the use of role plays.

- If they wish, family members can act out the situations discussed in the previous activities in this module. Other family members, using the handout, watch and judge whether the participants in the role play used the six steps of negotiation and how well they did each step. The family may have other situations in their lives, not previously mentioned, where they need to negotiate; these situations can also be used in the role plays. Each family member should participate in at least one role play.

- After each role play, discuss what happened. The following questions can be used to guide the discussion.

  1) How did it feel to do the role play?

  2) Were the steps of negotiation used?

  3) Could anything have been done differently?

  4) Were you satisfied with the solution?

  5) Is there another solution to the problem not mentioned by the participants in the role play?

- The following scenarios can be used for further practice or in place of the previously discussed negotiation situations. They are set up so that the person doing the negotiation needs to offer a compromise to the person with which they are negotiating:

  1) A child or adolescent in the family has been assigned extra chores. The person receives an allowance based upon the chores he/she already does. The person feels entitled to a raise in allowance because of the increased work. The parent who assigned the extra chores did not say anything about getting more money.

  2) A family member needs to ask the boss for permission to leave work early on Friday afternoon to go out of town with the rest of the family for the weekend. The family member does not want to lose any money by working fewer hours.

  3) A member of the family will not be able to hand in an important homework assignment on time because he/she was sick for most of the week. The person needs to negotiate with the teacher a way to complete the assignment without having points taken off for handing it in late.

  4) The family has only one television set. Two members of the family have favorite programs on at the same date and time. They need to negotiate or neither one of them will be able to watch their program if they keeping fighting about it.

It is especially important that the young person with a disability have opportunities to practice negotiation skills in this activity.

5) One activity that all family members enjoy is going out to dinner, but everyone has different tastes in food. They have not been going out as a family because they cannot agree on where to go. The family as a whole needs to work out a compromise.

Review and Reflect

- How can the skills you just practiced be incorporated into your life and your family life as a whole?
- What steps can you take to do this?

Preparation for Next Module

- Distribute handouts duplicated from pages 130-35 at the end of Module 12. Ask the family to read them in preparation for the next session.
- Ask the youth/young adult with a disability to think about an area of change or a personal goal he/she desires within his/her school program. This will form the focus of a person-centered plan to be developed in the next module.
- Ask family members to document or just remember situations where they act as personal advocates and situations where they observe other family members acting as personal advocates between this session and the next.
- Photocopy role play scenarios (page 136 at the end of Module 12), cut apart, and fold. To be used during next session.
- In preparation for the IEP role play activity make place cards with the titles of IEP team members (Special Education Teacher, Principal or Administrator, Parent(s), Student); other possible titles are Occupational Therapist, Physical Therapist, Speech/Language Clinician, Guidance Counselor, School Psychologist, School Social Worker, and Work Coordinator.
- Acquire and preview the videotapes, *Speak Up for Health* and *Four Easy Pieces* to be shown in the next session. (*Speak Up for Health* is available from PACER Center, Minneapolis, (612) 827-2966. *Four Easy Pieces* is available from Advocating Change Together, St. Paul, (612) 641-0297).
- Identify dates, times, and locations of local self-advocacy meetings.

Conflict resolution allows the family to deal constructively with differences and problems that may arise as people advocate for themselves, the topic of the next module.

Supplemental Information

Six Steps of Negotiation

1) Recognize that you are in a situation that has the potential for conflict.

2) Identify what the main source of disagreement is and why the other person is upset.

3) Listen to what the other person is saying.

4) Present your side, calmly, and see how the other person reacts.

5) Talk about alternative solutions and offer a compromise.

6) Enact the compromise.

12 Advocating for Yourself

Introduction

Personal advocacy refers to speaking out for or acting on behalf of oneself or others, either alone or with a group. It can range from making sure that your viewpoint is understood by other family members when discussing vacation plans, to taking part in organized rallies and demonstrations to ensure that your government representatives are aware of your views about a specific issue. To successfully advocate for oneself or others, an individual must be aware of the desired outcomes of a situation, possess well-developed assertive communication skills, have in-depth knowledge about the issues at hand, and have the motivation and confidence to speak out. In addition, one must also be aware of one's rights as a citizen and take responsibility for acting in a constructive manner when those rights are infringed upon by others.

Although the potential to advocate for oneself is within all human beings, it is not an all or nothing phenomenon. Some individuals advocate for themselves extremely well across a wide variety of situations. Others may be able to advocate for themselves in specific situations on certain issues. Some persons may be capable of personal advocacy in only limited situations and may require a great deal of support. Many persons with disabilities, at least until they have had the opportunity to practice and refine the necessary skills, fall into this last category.

Personal advocacy happens when a person is empowered. Empowerment occurs when individuals have the support, training, and encouragement to speak for themselves, to make their needs and wants known, and to take steps to meet needs and reach goals. For youth/young adults with disabilities, their families are one essential resource for personal advocacy skill-building and support.

Overview of the Module

This module addresses personal advocacy within three areas. The first area deals with how the family defines personal advocacy, the strengths members see in one another, and ways in which they can begin to support the practice of personal advocacy. In the second area, personal advocacy within the context of various planning meetings and in the health care system is discussed. In the third area, the family identifies practical examples in their own lives where personal advocacy can be practiced. This module is designed to be completed in two sessions of approximately two hours each.

Module Goals

- *Family members will describe what personal advocacy means to them.*
- *The family will gain a broader perspective on individualized planning processes, and means to enhance its involvement in and exercise of self-determination within the processes.*
- *The family will identify opportunities to practice personal-advocacy skills.*

Module Objectives

- *Family members will define and discuss ways that they see themselves and other family members acting as personal advocates.*
- *Family members will describe situation(s) in which they have advocated for themselves or observed other family members advocating for themselves.*
- *Family members will identify and discuss their personal advocacy role models.*
- *Family members will learn how to be personal advocates within the context of the health care system.*
- *The family will identify key components of the IEP process and other service plan processes.*

Module Objectives, cont.

- *The family will identify and develop strategies to increase its support of the youth/young adult with a disability in order for that individual to participate more fully in the development of service plans.*
- *One or more family members will attend a self-advocacy meeting.*

Module Activities

- *Personal Advocacy Role Play*
- *Experiences with Personal Advocacy*
- *Naming a Personal Advocate Role Model*
- *IEP Role Play*
- *Person-Centered Planning Simulation*
- *Speak Up for Health Videotape*
- *When to Use Personal Advocacy*
- *Attending a Self-Advocacy Meeting*

Activity Plans

Activity 1: Personal Advocacy Role Play

Introduction

We all advocate for ourselves on a regular basis in order to access what we want and need. This activity is designed to assist family members in identifying their own and other's personal advocacy styles. This process is meant to help the family members see ways to maximize their own skills and learn from the skills of others.

Materials Needed

Copies of role play scenarios (see page 136 in Supplemental Information at the end of this module); copies of *Definitions of Personal Advocacy* and *Practical Examples for Implementing and Enhancing Personal Advocacy Skills* (see pages 130-33 in Supplemental Information at the end of this module) to be handed out at the end of the previous session; paper, pen, flipchart. Optional: Camcorder, monitor, and videotape.

Preparation for Facilitator

At the end of Module 11 distribute copies of the handouts *Definitions of Personal Advocacy* and *Practical Examples for Implementing and Enhancing Personal Advocacy Skills* (see pages 130-33 in Supplemental Information at the end of this module). Photocopy role play scenarios (see page 136 at the end of this module), cut apart, and fold in half.

Preparation for Family

Read handouts *Definitions of Personal Advocacy* and *Practical Examples for Implementing* and *Enhancing Personal Advocacy Skills* (see pages 130-33 in Supplemental Information at the end of this module).

Instructional Procedure

- Introduce this module and activity by discussing the definition of personal advocacy in the handout (page 130 of the Supplemental Information at the end of this module). Also talk about the importance of personal advocacy (base your comments on the information in the Introduction to this module on page 117).
- Explain that the first activity is a role play of personal advocacy situations, and that its purpose is to help the family members identify their personal advocacy styles.

- Place the role play scenarios in a container and have each participant withdraw one slip. The participant will act out the scenario first as themselves, and secondly, assuming the role of another family member. You or a family member can role play the other person in the activity.
- Upon completion of the role play, ask the family to discuss the personal advocacy skills and styles that have been displayed. Discuss how the styles of family members in the role play were similar and different. The following questions may be used to stimulate discussion if needed:

  1) What was your impression of the role playing?

  2) What skills, words, and actions did you observe that you feel would support personal advocacy?

  3) How could these skills, words, and actions be effectively incorporated into other appropriate situations?

  4) What skills, words, and actions did you observe that you feel would not support personal advocacy?

  5) Are there personal advocacy situations where specific skills, words, and actions may work for one person and not another?

- Ask family members how the strengths they see in one another's skills could be helpful in their own quest for more effective personal advocacy skills. You may want to chart key points that arise (if a videotape was made, review and critique).

Review and Reflect

- Discuss how the role plays in which family members just participated demonstrated ways individuals could gain control over various situations.
- What is the importance of personal control in one's own life?
- Identify areas in which the family members could advocate to gain more control in their lives.

Activity 2: Experiences with Personal Advocacy

Introduction

We don't always realize when we are actually in the process of advocating for ourselves. This activity is designed to assist family members to identify those times in their lives when they actually have needed to use personal advocacy skills, as well as to see when other family members use those same skills. This will help highlight the use of personal advocacy in the quest for self-determination.

This module addresses personal advocacy, speaking out or acting on behalf of oneself or others.

Materials Needed

Paper, pen, flipchart.

Preparation for Facilitator

None.

Preparation for Family

The family should document or just remember situations where they acted as personal advocates and situations where they observed other family members acting as personal advocates between the last session and this one.

Instructional Procedure

- Ask family members to take turns describing situations that occurred since the last session in which they acted as personal advocates or witnessed other family members doing the same. The following questions may be used to stimulate discussion:

  1) Describe the situation(s) where you have acted as a personal advocate.

  2) Are there aspects of the personal advocacy situation that you would like to change? If so, why and how?

  3) How did you feel about the outcomes of the personal advocacy?

  4) Describe the situation(s) where you observed another person acting as a personal advocate.

  5) Are there aspects of that personal advocacy situation that you would like to see changed? If so, why and how?

  6) How did you feel about the outcomes of the personal advocacy in which this individual engaged?

- Ask the family members to identify any additional personal advocacy skills they've seen in themselves and others through these experiences. Discuss how they can strengthen and build on those skills in their own lives.

Because of culture, religion, gender or one's family background people view speaking up for oneself in different ways. Discuss any family beliefs that may hinder the support of self-advocacy by all family members.

Review and Reflect

- When and why do you use personal advocacy skills?
- What effect did using personal advocacy skills in certain situations have upon the amount of control you felt that you had over your life at that point?

Activity 3: Naming a Personal Advocate Role Model

Introduction

A great deal of social learning takes place through the observation and imitation of the behavior of role models. Through identifying personal advocacy role models and their admired advocacy skills, the family will reinforce the value of personal advocacy and identify skills that family members would like to develop. This will help the family members understand one another's views of personal advocacy as well as highlight similarities in those views. With this understanding they may be better equipped to support each other in the development of those advocacy skills, increasing opportunities for the expression of self-determination.

Materials Needed

Paper, pen, flipchart.

Preparation for Facilitator

None.

Preparation for Family

None.

Instructional Procedure

- Ask family members to identify or describe their ideal personal advocate role models, the traits they respect in these people, and steps family members can take to incorporate those traits of their role models into their own lives. The following questions may be used to stimulate discussion:

  1) Identify or name your ideal personal advocacy role model.

  2) What personal advocacy traits of this individual do you respect?

  3) What strategy can be planned in order to incorporate and support the progress of these personal advocacy traits being included into your life?

Review and Reflect

- What are the similarities and differences between the role models chosen by different family members?
- What are the similarities and differences between your personal advocacy style and the style of your role model?
- How do these styles affect an individual's self-determination?

Through identifying personal advocacy role models and their admired advocacy skills, the family will reinforce the value of personal advocacy and identify skills that family members would like to develop.

Activity 4: IEP Role Play

Introduction

Throughout the course of their lives, persons with disabilities attend many meetings that involve program planning and goal setting, whether they be educational, vocational, medical or in other areas. Being able to advocate for themselves in those meetings will increase the probability that the goals reflect the needs and desires of the individual rather than those of the service provider or family. The earlier the individual with a disability participates in some capacity in such meetings, the easier it will be to take primary responsibility for his/her life as an adult. The family plays a crucial role in the development of personal advocacy skills by providing opportunities to practice these skills in a supportive environment. To practice and enhance development of personal advocacy skills, in this activity the family will role play an IEP meeting in which a conflict of opinion has arisen.

Materials Needed

Cards with titles of IEP team members (Special Education Teacher, Principal or Administrator, Parent(s), Student; other possible participant titles are Occupational Therapist, Physical Therapist, Speech/ Language Clinician, Guidance Counselor, School Psychologist, School Social Worker, and Work Coordinator). Paper, pen, flipchart. Optional: Camcorder and monitor to videotape the session.

Preparation for Facilitator

Make name cards for titles of IEP team members (see Materials Needed).

Preparation for Family

None.

Instructional Procedure

- Explain that youth/young adults with disabilities typically have a number of formal plans for various services and supports they receive from educational, social service, vocational, and health systems. For all plans there are varying opportunities for participating in the planning process and advocating for oneself. This activity will look at a specific plan - the IEP - and ways that the individual can exercise self-determination within the traditional educational planning process.
- Ask if the youth/young adult with a disability and his/her family knows what is in the person's Individual Education Plan (IEP), when it needs to be reviewed, and how it was developed. Discuss ways that the individual and his/her family have already participated in development of the plan.

The family may be inexperienced in the IEP process and need further explanation and guidance in the role-playing.

- If the family has not recently taken part in an IEP session, briefly review the process with them and explain the roles and responsibilities of specific team members.
- Set the stage for the role play by describing the following scenario: You are at an IEP meeting; the focus person feels strongly about having a self-determination goal on his/her IEP, but no one else on the team supports the inclusion of such a goal. The group must come to agreement on the answer to this question: "What self-determination goals should be included in the IEP?"
- Each family member will role play a member of the IEP team; provide each with a card showing their title. If the role play has not concluded within 10 minutes ask the participants to stop without resolution.
- Discuss family observations of the personal advocacy skills that team members utilized when trying to make their point in the team meeting. (If a videotape was made, review it at this time.)
- Discuss ways to enhance existing skills and develop new skills. Document key points. The following questions can be used for discussion: "What steps in the planning process are empowering to the focus person's self-determination?" and "How can the family support fuller participation of the youth/young adult with a disability in IEP development and implementation?"

Review and Reflect

- What other service plans have been or could be developed for the youth/young adult with a disability in various systems (vocational, county case management, health care, etc.)?
- What steps can the family take to support the young person in advocating for him/herself in the development of service plans within those systems?

Activity 5: Person-Centered Planning

Introduction

For many years, schools and other service agencies have planned for the futures of persons with disabilities without fully including these individuals or their families as partners in the planning process. The manner in which individualized educational programs are developed is an example of this approach. For the most part, what happens in such situations is that the professionals involved meet beforehand, discuss student progress, needs, and the results of any assessments, and then develop an informal intervention plan. When the IEP team meets with parents, this plan is presented to them and their questions answered. At this time, parents are expected to sign the plan giving

To truly exercise personal advocacy, individuals must move beyond wishing for change or simply identifying desired changes, and take action to bring about what they desire. Person-centered planning is one way to do that.

the school permission to begin implementation. The major weakness of this traditional approach is that it fails to make use of years of "expertise" and knowledge about the capacities, needs, and dreams of the student possessed by the student with the disability, his/her parents, and other family members.

Person-centered planning is an alternative approach that can be used to help plan for the future of students with disabilities. This process is based on the assumption that individualization, the involvement of family and friends, flexibility, and true collaboration between family and school are necessary ingredients for the creation of a desirable future for students with disabilities. The family with whom you are working has already participated in the development of a person-centered plan, the Personal Futures Plan in Module 2. This activity is designed to give the family an additional opportunity to practice person-centered planning, with family members themselves serving as facilitators.

Materials Needed

Copies of handouts, *Facilitating the Person-Centered Planning Process, Guidelines for Quality Person-Centered Planning,* and the *Person-Centered Planning Role Play Form* (see pages 133-35 in the Supplemental Information section at the end of this module) to be distributed at the end of the previous module; the flipchart maps created for the youth/young adult with a disability in Module 2; paper, pen, flipchart.

Preparation for Facilitator

Review the maps created by the youth/young adult with a disability in Module 2. This information can be used in this activity so that the family can focus on developing action plans rather than going over background information. At the end of the previous module, distribute copies of *Facilitating the Person-Centered Planning Process, Guidelines for Quality Person-Centered Planning,* and the *Person-Centered Planning Role Play Form* (see pages 133-35 in the Supplemental Information section at the end of this module).

Person-centered planning is an alternative to the typical service plan development process. It may be new not only to the family, but also to the service providers with whom they're involved. It is important that the family be aware of this.

Preparation for the Family

The family will read *Facilitating the Person-Centered Planning Process* and *Guidelines for Quality Person-Centered Planning* (see pages 133-34 in the Supplemental Information section at the end of this module). In addition, the youth/young adult with a disability will identify an area of change or a goal that he/she would like to work on in his/her school program. This will form the focus of the person-centered plan to be developed in this activity.

Instructional Procedure

- Explain that professionals (e.g, teachers, rehabilitation staff etc.)

typically develop service plans for young adults with disabilities with little input from the student him/herself. Let the family know that this isn't necessarily the way it has to be and reintroduce the idea of person-centered planning.

- Review and discuss the handouts *Facilitating the Person-Centered Planning Process* and *Guidelines for Quality Person-Centered Planning* (see pages 133-34 in the Supplemental Information section at the end of this module). Ask the family to identify the ways that the process described in the handouts is similar to and different from their experiences with development of service plans.
- Set the stage for the person-centered planning process by explaining that the family is about to role play an alternative to the typical IEP meeting, a person-centered planning process focusing on school services. Ask the young person with a disability to state the personal goal or area of change he/she has identified. Refer to flipchart maps developed in Module 2 if needed. If the goal appears too broad, guide the individual through narrowing it; if it is too narrow, assist him/her to expand it.
- Ask family members to volunteer as facilitators for the person-centered planning process. If no one volunteers at first, agree to get the process started yourself but ask others to commit to spending at least some time in the facilitator role.
- With minimal direction, guide the family through the stages of the person-centered planning process, having them use the *Person-Centered Planning Role Play Form* (see page 135 in the Supplemental Information at the end of this module). If they seem unsure about where to start, ask them to refer to the handout. If they initiate the process and then seem to get "stuck," allow them to remain stuck for awhile before providing assistance. Remember, it is only through learning how to progress beyond barriers on their own that the family will acquire the skills to independently use this process in the future.
- If family members do not appear to be nearing a conclusion by the end of the session, ask them to discuss the possibility of continuing the planning process the next session.
- Upon completion of the plan, ask family members to talk about how they felt about the experience, and whether they are satisfied with the plan developed. Be especially sure to solicit the opinions of the young adult in the family in this regard.
- Invite the family to look back at the process and discuss what went well and what did not go well, the strengths they displayed and areas they may need to continue to develop.

The youth/young adult with a disability is at the center of this planning process. Make sure that he/she has the opportunity to speak first and is listened to.

Review and Reflect

- Ask family members to reflect as to how the use of a person-centered planning process could facilitate the self-determination of the youth/ young adult with a disability. What other areas of the person's life would lend themselves to this approach?

- What steps does the family need to take in order to use this person-centered approach to planning in school or other service settings?

Activity 6: *Speak Up for Health* Videotape

Introduction

There are times when practicing personal advocacy can be intimidating. One such time is when dealing with the health care system. To help increase its personal advocacy in regard to health care, the family will view the *Speak Up for Health* videotape and discuss ways to increase its personal advocacy in relation to health care.

Materials Needed

The videotape *Speak Up for Health* (to order, contact PACER Center, Minneapolis (612) 827-2966); VCR and monitor; paper, markers, and flipchart.

Preparation for Facilitator

Acquire and preview the videotape *Speak Up for Health*, and will bring video playback equipment.

Preparation for Family

None.

Instructional Procedure

- Introduce this activity by explaining that one area of life in which individuals need to advocate for themselves is in health care. The videotape will present ideas on how to do that.

- View the videotape. Discuss any new information presented in the program and how the information presented can be applied to the family members' lives. The following questions may be used to stimulate discussion:

  1) What interesting information did you gain from this video?

  2) What information would you like to follow through on or possibly incorporate into your life as an individual? What information would you like to see incorporated for another family member or for the entire family?

  3) How can this be incorporated? What are the first steps to incorporate this information? Who will do what?

The health care system can be one of the most essential and most intimidating settings in which to practice personal advocacy. Learning skills to use there can empower families to advocate in all areas of their lives.

4) Was there information that may be applicable to one family member and not another? Explain what that is and why you feel this way.

Review and Reflect

- How important is it to have self-determination in this area of your life?
- How would gaining more control over this aspect of your life enhance self determination in other areas of your life?

Activity 7: When To Use Personal Advocacy (Optional)

Introduction

Note: The videotape *Four Easy Pieces* was developed with the goal of teaching self-advocacy skills to individuals with cognitive disabilities. If the youth/young adult in the family with whom you are working has a different type of disability, carefully preview this videotape for appropriateness.

Exactly when do we use personal advocacy skills? This is a good question since there are so many individual differences in the how and when of using personal advocacy. This activity is designed to identify situations when personal advocacy can and should be practiced. The family will view a videotape and generate examples from their own and others' lives that illustrate beneficial uses of personal advocacy.

Materials Needed

Paper, pen, flipchart; VCR, monitor and videotape *Four Easy Pieces* (available from Advocating Change Together, St. Paul, Minnesota, (612) 641-0297).

Preparation for Facilitator

Preview the videotape, *Four Easy Pieces.*

Preparation for Family

None.

Instructional Procedure

- Introduce this activity by explaining that sometimes it is difficult to know when to use personal advocacy skills and to what degree. The family will view and discuss a videotape that may help them

Sometimes when people have been denied opportunities to speak for themselves, they don't know when to use personal advocacy skills and to what degree. This is another area where it is important to know that it's okay to make mistakes and learn from them.

clarify for themselves when and how to use personal advocacy.

- Begin this activity by viewing the videotape, *Four Easy Pieces*. Discuss how the information from the video could be used in the family members' lives. Identify times when skills from the video could be practiced. You may want to document information. The following questions may be used to stimulate discussion:

  1) Did the videotape give you examples of where personal advocacy could be used in your life?

  2) In what specific situations can you practice personal advocacy?

  3) What steps do you need to follow to practice or try personal advocacy?

  4) Are there any supports you need to implement this plan to practice or try personal advocacy?

- Ask family members to commit to practicing some of the skills and incorporating those with which they feel comfortable into their lives.

Review and Reflect

- How did the use of personal advocacy skills in the videotape enhance self determination?

- How could using these skills enhance the self-determination of family members?

Activity 8: Attend a Self-Advocacy Meeting (Optional)

Introduction

Note: This activity will be possible only in areas where there are self-advocacy groups.

Persons with disabilities can enhance their self-advocacy skills by participating in self-advocacy organizations. Participation in these groups not only results in personal growth, but also in improved services for persons with disabilities through political action undertaken by members. Attending a meeting will give family members further exposure to successful personal advocates and possible role models for the youth/young adult with a disability.

There is a growing national self-advocacy movement that supports self-determination by people with disabilities. This is one way that individuals with disabilities can connect with others to enhance self-determination.

Materials Needed

Dates, times, and locations of self-advocacy meetings.

Preparation for Facilitator

Identify dates, times, and locations of local self-advocacy meetings.

Preparation for Family

None.

Instructional Procedure

- Introduce this activity by explaining to the family that there are self-advocacy groups across the country that support people with disabilities in speaking up for themselves. Tell them about the self-advocacy groups in their area.
- Ask if any family members would like to attend a self-advocacy meeting. Have the family identify the needed level of support for one or more members to attend a self-advocacy group meeting, and problem-solve about any obstacles to attending.

Preparation for Next Module

- Copy and distribute the handout, *Networking* (see pages 143-44 in the Supplemental Information section at the end of Module 13), and the focus person's future map from Module 2 for review. Family members should think about the people they know, the type and frequency of contact they have with each, what networking means to them personally, and how they can strengthen their networking in order to enhance self-determination.
- Compile a *Systems Information Packet* for each family member containing information about the systems providing services for persons with disabilities and their families in your area. The sheet, *Materials in the Systems Information Packet* (see page 146-4 in the Supplemental Information at the end of Module 13) provides a sample. In addition, at the end of this module ask the family what services they want more information about, and include information on those systems in the packet.
- Make a copy of the *Family Network Form* (see page 145 in the Supplemental Information section of Module 13) to be filled out during the next session.

Advocating for oneself is the basic skill used in connecting with resources available in the community, the topic of the next module.

Supplemental Information

Definitions of Personal Advocacy

- Personal advocacy refers to the need for each person to assume responsibility for the protection of his/her own rights and interests.

- Personal advocacy is advocacy by an individual whose rights are at risk of being violated or diminished, in order to represent their own rights and interests and speak on their own behalf. The means by which an individual speaks or expresses him/herself may vary from person to person and should be respected and supported. This definition is based on certain basic assumptions:

  1) The Constitution of the United States guarantees every citizen equal rights, equal opportunities, and equal protection under the law.

  2) The rights of citizenship can only be limited or denied through due process in a court of law.

  3) All citizens should be informed of their human civil rights.

  4) An understanding of human and civil rights and responsibilities is essential to successful integration into the community.

- The process of understanding rights, assuming responsibilities and advocating for oneself involves uncertainty, skill acquisition, practice, frustration, and risk.

- Personal advocacy means: "We are speaking for ourselves; no one else can do as well..." Bonnie Shoultz, self-advocate

- Personal advocacy means: "The elements of choice determine the success of an individual making choices in their daily living environment. These elements include one's level of education, one's lifestyle and a belief system that can lead to a creative life. Personal advocacy is a lifelong process that will give order to an individual's world." Dennis J. Campbell, self-advocate

- "People have the right to discover, explore, and experience life. The manner in which a person chooses to experience life may be inconsistent with our philosophy. These differences need to be simply acknowledged and appreciated. No value judgment is necessary." Hayden, M. Confessions of a Professional. *IMPACT: Feature Issue on Self-Advocacy* (Winter, 1990/91). Minneapolis: Institute on Community Integration, University of Minnesota.

- Effective personal advocacy is empowering people and people empowering themselves to speak for themselves. *Effective Self-Advocacy: Empowering People with Disabilities to Speak for Themselves* (1990). Minneapolis: Research and Training Center on Residential Services and Community Living, University of Minnesota.

Practical Examples for Implementing and Enhancing Personal Advocacy Skills

Speaking for yourself begins in day-to-day life. To learn to act as a responsible individual, other people have to see and treat you as a responsible individual every day. A person's ability to speak for oneself is enhanced when:

- Others hold the expectation of people making choices, with the help they need to carry them out.
- Chances to choose have to be part of a person's life from the very beginning.
- Others firmly believe that the person has the right to choices, both in everyday life and in setting life goals.
- Others do not label the person, but get to know the person for oneself.
- Others ask and listen with care to what the person wants, what the person's goals are, what specific help the person needs and wants.
- Others focus on the person's capabilities, not the person's inabilities.
- Others match supports to the person, instead of fitting the person into what is available.
- Others provide a spectrum of possibilities to a situation, not just what you as a parent want of your child. Encourage the person to work on what the person wants, even if it is hard to see how far the person can go towards reaching a goal.
- Others work along with the person to find ways to make what the person wants possible, by helping with problem-solving and by connecting the person with others who can be trusted to help.
- Others realize that the person can learn from mistakes, that the person has the right to make mistakes, and receive the support to figure out what went wrong and how to move on.
- Others recognize that it's OK for the person to say, "I hate this. Let's start over!"

These recommendations sound simple, but it may not be the way day-to-day life has been or is for a person. At times, fear holds a person back from being a personal advocate. They have been intimidated by fear of punishment or failure and told they can't do things so often that they lack confidence. Empowerment is the answer to fear and silence. Empowerment equals personal and group connections plus information plus money.

From *Effective Self-Advocacy: Empowering People with Disabilities to Speak for Themselves* (1990). Minneapolis: Research and Training Center on Residential Services and Community Living, University of Minnesota.

- Empowerment means assisting individuals to learn how to make choices, creating an environment in which those choices will be honored, and giving individuals and families control of resources.

  From *Leadership for Empowerment* (1991. St. Paul: Minnesota Governor's Planning Council on Developmental Disabilities.

- Empowerment is an intentional, ongoing process centered in the local community, involving mutual respect, critical reflection, caring, and group participation, through which people who are lacking in an equal share of valued resources gain access to and control over those resources.

  From Cornell Empowerment Group. (December, 1990). Underlying assumptions in the empowerment process. *Futurity*. St. Paul: Minnesota Governor's Planning Council on Developmental Disabilities.

Once individuals have the support and skills to speak for themselves and work for choices in their own life, they may want to work to make change for others by doing the following:

- Becoming politically active.
- Defining their own positions.
- Forming or joining coalitions for change.
- Involving community leaders in their lives and in the issues. If we push ourselves to reach out and ask specifically for the help we need to take action, some people will help.
- Influencing the media.
- Participating in councils, boards, alliances, coalitions, task forces, and committees. There is power in numbers.
- Reaching out into the community for help.

From *Effective Self-Advocacy: Empowering People with Disabilities to Speak for Themselves* (1990). Minneapolis: Research and Training Center on Residential Services and Community Living, University of Minnesota.

Once personal advocacy skills are acquired, they must be practiced in order to be maintained and enhanced. Some strategies to practice, maintain, and enhance personal advocacy skills are:

- Continually examine the conditions of one's life.
- Review the importance of being aware of the alternatives Once individuals examine the conditions in their lives and have identified some things they want to do or want changed, they must review the alternatives and begin making choices.
- Raise questions and identify and solve problems through communication of needs, wants, and feelings to others. It is important to communicate what you want to the appropriate person.
- Seek advice, counsel, and support through various community resources. Continue to expand and nurture that network of resources, recognize that friends, family, neighbors, co-workers, etc.

can provide moral support as well as help in identification of services and resources.

Facilitating the Person-Centered Planning Process

Person-centered planning is a relatively new planning process that uses the natural supports available to an individual with disabilities to help create and implement programs that lead to achievement of personal goals. This process helps define the kind of training, assistance and support that should be provided and it takes into consideration the entire life of the individual, including strengths, dreams, aspirations, joys, needs and concerns. Person-centered planning is, therefore, an alternative planning strategy that keeps the individual and his/her life vision foremost in mind when planning for the present and future.

Although it is traditional for service system representatives to convene and lead most service planning meetings, this does not necessarily have to be the case. Individuals with disabilities and their families can also initiate and guide the meetings when they feel the necessity to do so. The person-centered planning process may be new to a service system, and therefore it may be necessary for the individual and family to take the lead in calling a meeting and in facilitating it. In such cases the family may also want to enhance a system's ability to use the process by suggesting to the service provider resources that describe person-centered planning (such as the publication *It's Never Too Early, It's Never Too Late*, published by the Minnesota Governor's Planning Council on Developmental Disabilities, St. Paul, (612) 296-4018).

The person-centered planning process is composed of the following seven major steps:

- **Identifying a Goal or Desired Change**. The individual with a disability or other family member experiences the desire to bring about a change in an area addressed by the service plan or to incorporate a personal goal into the plan.
- **Organizing the Planning Meeting**. Ideally, the individual, their family, and the service system collaborate in organizing the meeting to address the desired goal or change. The individual and their family have primary responsibility for determining who will take part in the meeting. Possible participants include the individual, parents/guardians, advocates, service providers, friends, and relatives.
- **Setting Goals and Objectives for the Meeting**. Prior to the person-centered planning meeting, the individual with a disability and their family, in collaboration with the service system, creates a set of goals and objectives that identify the purpose of the meeting and what is to be accomplished during it.

- **Gathering Information**. During the meeting, the participants gather information about the individual's abilities and support needs in relation to the changes or goals he/she desires within the service plan.
- **Prioritizing**. Early in the meeting participants prioritize the issues/concerns brought to the meeting, selecting a limited number to be addressed during the meeting.
- **Developing an Action Plan**. Taking into consideration the desired changes/goals of the individual with a disability, as well as any related issues that must be dealt with, the participants create an action plan that will help the individual achieve that which he/she desires. Following the meeting, that plan is implemented.
- **Evaluating Outcomes**. At a variety of intervals following implementation of the plan, it is necessary for the individual, his/her family, and the service provider to evaluate the degree of success that the individual is experiencing. If the plan is proving less successful than desired, the person-centered planning process can be initiated once again to make needed changes.

Based on Donnellan, A. and Graczyk, M.J. (1989). *How to Develop an Individual Plan*. St. Paul: Minnesota Governor's Planning Council on Developmental Disabilities.

Guidelines for Quality Person-Centered Plans

You may find the following guidelines for person-centered plans useful as you participate in planning meetings. This list may be the basis for questions you may want to raise, may pinpoint areas of agreement or disagreement, and may help you assure that the plan empowers the person for whom it is made.

- Is the plan age-appropriate? Would these skills be performed by a person without disabilities of the same chronological age?
- Is the plan community referenced (natural community settings)? If its objectives are met, will there be participation in a variety of integrated community settings?
- Is the plan functional (necessary for increased independence)? Do the activities involve mutual interaction with peers without disabilities?
- Does the plan apply skills to several situations? Are skills taught or performed with natural cues and reinforcement?
- Does the plan support choice (individual strengths, needs, and preferences)? Do the objectives reflect the individual's choice and interest?

Adapted from *Guidelines for Quality Individual Plans* (1987). St. Paul: Minnesota Governor's Planning Council on Developmental Disabilities.

Person-Centered Planning Role Play Form

To the Family: The following questions will guide you through the role play of the person-centered planning process as it could be used within the school system. The questions are based on each of the seven steps of the process (see the handout, *Facilitating the Person-Centered Planning Process*), and are to be answered by the youth/young adult with a disability in collaboration with the other meeting participants. You may find it helpful to write each on the flipchart, listing the responses under each.

1) What do I want to change about my school program? Is there a goal I want to reach?

2) Who would I like to have at my planning meeting to support me?

3) What do I want to have happen at the meeting?

4) What can I already do to accomplish the change or goal in my school program? What can I do with assistance? What do I need to learn to do? What will others have to do?

5) What are the most important things that have to happen if I am going to make the change or reach my goal?

6) How can I reach my goal or make the change? What needs to happen and who can support me?

7) How and when will I know if I am getting closer to what I desire? If this plan doesn't work, what will I do to improve things?

Role Play Scenarios

Copy the following and cut on the line between each activity. Then fold in half. Have each family member draw a role play scenario slip and (1) role play how they would act as a personal advocate and (2) role play another family member. The facilitator or a family member can role play the other person in the activity.

Scenario 1:

You go to have your driver's license renewed and the clerk is very uncooperative.

Scenario 2:

You purchased an item for $5.00, you give the clerk $10.00, the clerk does not give you any change and insists that you gave him/her $5.00, not $10.00.

Scenario 3:

You go for a physical with a new doctor and you feel s/he did not respect your independence and skills because they would not answer your questions or share any of the test results with you.

Scenario 4:

You have applied for a job, and have all the requirements to do the job. You are called for an interview. During the course of the interview the employer says she cannot hire you even though you meet all the requirements because you have a disability.

Scenario 5:

During class or on the job your teacher/boss accuses you of being very disruptive, when in fact it was the person next to you. The person next to you blames you for being disruptive.

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13 Connecting with Community Resources

Introduction

Linking families with their community resources is an important part of building support for the exercise of individual and family self-determination. Creating networks of resources is not easy, but the gains are well worth the time and effort. The resources a family and individual develops when establishing linkages can enhance the control a family or individual has over their lives and broaden the options from which they can select.

The systems that young people with disabilities and their families commonly work with include the school, health care, higher education, county human services, and vocational rehabilitation systems. Up to this point, depending on the nature and severity of the young person's disability, involvement may have been primarily with only the school system. During the transition years, the emphasis shifts from educational programming to planning for adult life in the community. This necessitates seeking the services of one or more systems other than school, such as vocational rehabilitation and case management services. The more an individual and family knows about each of the systems and how they work, the more effectively they can use the systems to meet their needs and reach their goals. The key to linking families and systems in a way that supports self-determination is *networking*. Networking refers to developing contacts and positive relationships with individuals within each system, as well as with advocates and others outside the systems who are knowledgeable about navigating specific systems. By making these connections individuals and families can effectively work within systems and between systems to gain the services and supports they need.

Overview of the Module

This module focuses on helping the family gain a broader understanding of how various systems work, and of the resources and supports various systems have to offer. It will first focus on resources within the community. The family will identify areas where it feels it could benefit from the use of different resources, identify those resources, and identify the people or organizations it needs to connect with to meet its needs. The second major focus of the module is on specific systems: how they may impact one's life and how to effectively work within them. The module is designed to be completed in one session of approximately two hours.

Module Goals

- *The family will gain a broader perspective on the resources in its community, identifying those that could be used to support self-determination, and the means to make connections with them.*
- *The family will gain a broader understanding of how a specific system impacts or may impact its life.*

Module Objectives

- *Family members will identify areas where they could benefit from receiving resources.*
- *The family will gain a broader perspective of why and how to network in order to enhance members' self-determination.*
- *The family will review information on systems that may impact the youth/young adult with a disability.*

Module Activities

- *Using Resources to Fulfill the Personal Futures Plan*
- *Networking*
- *Accessing Systems for Support*

Activity Plans

Activity 1: Using Resources to Fulfill the Personal Futures Plan

Introduction

There are times in every person's life when having the appropriate supports in place will make the practice of self-determination flow more smoothly. The focus of this activity is to assist family members individually and as a family unit to identify the areas in which they could utilize supports. They will identify what kind of resources could provide that support and how they would like the support delivered. The family will explore options, gaining a broader perspective on available resources.

Materials Needed

Paper, pen, and flipchart; the handout, *Networking* (see pages 143-44 in the Supplemental Information at the end of this module); the focus person's future map from Module 2, and the future maps for other family members developed in Module 9, Activity 1.

Preparation for Facilitator

At the end of the previous session, copy and distribute the handout, *Networking* (see pages 143-44 in the Supplemental Information at the end of this module), the focus person's future map from Module 2, and the future maps for other family members made in Activity 1 of Module 9. Read the information in the Supplemental Information section at the end of this module.

Preparation for Family

The family will read the handout, *Networking* (see pages 143-44 in the Supplemental Information at the end of this module), review the focus person's future map from Module 2, and review the future maps for other family members developed in Activity 1 of Module 9.

This module focuses on helping the family gain a broader perspective on and understanding of how various systems work, and of the resources and support various systems have to offer.

Instructional Procedure

- Introduce this module and activity by describing the importance of family connections with outside resources (base your comments on the information in the Introduction to this module on page 137). Explain that this first activity will focus on accessing outside resources to support the Personal Futures Plan of the youth/young adult with a disability.

- Review the handouts and the futures maps. Ask the family the following questions, writing answers on the flipchart:

1) In what areas of your life would you as an individual family member benefit from receiving supports or resources to enhance your self-determination? Please be as specific as possible.

2) From your own personal experience or from the materials you've read, please identify specific resources that you feel would meet your needs in these particular areas.

3) How would you go about accessing the resources? If you are not sure, how could you obtain more information?

4) What steps will you follow to access the identified resources?

5) Who will do what in order to access the identified resources? What will your timeline be?

6) If there were particular areas in your life in which no resources could be identified, how would you go about finding out about other possibilities for support?

Review and Reflect

- How can the identified resources enhance your or your family's self-determination beyond what you could do alone?

Activity 2: Networking

Introduction

Networking can seem like a difficult task and complicated process. Through this activity, a visual display of the family's current networks will be created. This will allow family members to see just how much they have already been networking. It will also allow them to see where their networks are and how they may or may not overlap. This visual display of the family's networking will help them gain a broader perspective of why and how they network.

Materials Needed

Paper, pen, colored markers, flipchart; *Family Network* form (see page 145 in Supplemental Information at the end of this module).

Preparation for Facilitator

Make a copy of the *Family Network* form (see page 145 in the Supplemental Information section at the end of this module).

Preparation for Family

Prior to the session, the family should read the handout, *Networking* (see pages 143-44 in the Supplemental Information section at the end of this module). Family members should think about the people they know and the type and frequency of contact they have with each

Networking requires a lot of energy and time. For a family that is already having difficulty keeping up with the demands of life, it may be helpful to identify small, manageable steps it can take in building networks.

person. Family members should think about what networking means to them and how they can strengthen their networking in order to enhance self-determination.

Instructional Procedure

- Introduce this activity by explaining that one way to identify and connect with resources is by networking.

- Review the handout, *Networking* (see page 143-44 in the Supplemental Information section at the end of this module), discussing the definition and benefits of networking.

- In round robin fashion, ask each family member to identify people with whom he/she has contact, who those people are, where they have contact, and how often they have contact. Track this information on a large group chart (each family member's contribution should be in a different color). Continue the process until you have exhausted each family member's network.

- Discuss the similarities and differences within each person's network. The following questions may be used:

  1) How much time and effort do you put into developing your network?

  2) What are some of the strategies you use for networking? Discuss why you network, in what situations you network, situations in which you would not network, what you get out of networking, what you give to a situation when you network, how you nurture the contacts, and linkages you develop when networking?

  3) How does your networking enhance self-determination?

  4) How could individual family members or the family as a whole support the networking for the youth/young adult with a disability?

- With each family member discuss creating a plan for using networking in his/her life. Ask each to identify the steps he/she needs to take to network, where networking can take place, with whom networking will take place, and how the contacts will be nurtured.

- For all family members with networking plans, ask them to identify the first step they will take in order to network, when they will take that step, and how they will monitor the progress they are making with networking.

- At the end of the session, go through the *Family Networking* form (see page 145 in the Supplemental Information section at the end of this module) with the family, and fill out the form based on the information provided in this session (or if the family prefers, leave the form with the family to complete later).

The youth/young adult with a disability should be given the first opportunity to talk about his/her networking opportunities and needs.

Review and Reflect

- How could expanding your current networks further enhance your exercise of self-determination?

Activity 3: Accessing Systems for Support

Introduction

Systems, such as social service, school, and health care systems can seem confusing and complicated, creating a barrier preventing people from using the various systems to their fullest. To help the family members learn to make systems work for them, this activity reviews the resources that are available and their purposes. The family will especially focus on reviewing information on systems that now or in the future could impact the youth/young adult with a disability.

Materials Needed

Paper, pen, flipchart; *Systems Information Packet.*

Preparation for Facilitator

Compile a *Systems Information Packet* containing information about the different systems that provide services for persons with disabilities in your area. The sheet, *Materials Included in the Systems Information Packet* (see page 146-47 in the Supplemental Information at the end of this module) identifies materials in the packets used by the developers of this curricula. These are provided as examples of what you may want to include in your packet. In addition, at the end of the previous module ask all family members what services they want more information about, and include information on those systems in the packet. Make a copy of the packet for each family member.

Preparation for Family

None.

Instructional Procedure

- Introduce this activity by distributing and discussing the *Systems Information Packet* you developed. Explain that it contains information related to those services about which the family requested information. As you look through the information on various systems, use the following questions for discussion:

  1) In your own words, describe or explain this system.

  2) Is this a system that the youth/young adult with a disability or other family member could possibly benefit from using?

Systems, such as social service, school, and health care systems, can seem confusing and complicated. In this activity, participants practice a process for accessing systems, a process they can continue to use after the curriculum is completed.

3) What did you see in this system that would support self-determination, and what would not support self-determination?

4) Does the youth/young adult with a disability or other family member receive services from this system? If you do not know, or are not sure, discuss ways that you could find out if a family member is receiving services.

5) If you receive services from this system, describe the services and whether they are delivered in a way that supports the recipient's self-determination.

6) If you receive services from this system, do you have a case manager? If you do not know, or are not sure, discuss ways that you could find this information.

7) If you are not receiving services from this system, but feel that services from this system would support self-determination, how would you go about applying to receive services from this system?

Review and Reflect

- How can systems enhance self-determination?
- How can systems hinder self-determination?
- What have been your experiences with systems and their effect on your self-determination?

Preparation for Next Module

- Copy and distribute the handout, *Power Analysis: An Overview* (see pages 156-57 in the Supplemental Information at the end of Module 14). Ask family members to write down the answers to the questions in the reading. They may draw on their own experiences in answering the questions, and may wish to build on this information by talking to others, or referring to newspapers and organization newsletters.
- Copy and distribute the handout, *Political Systems* (see pages 157-59 in the Supplemental Information at the end of Module 14). Ask the family to identify political organizations or bodies that are working on issues of interest to family members.
- Ask the family to think about possible opportunities for the youth/young adult with a disability to vote in an election at any level (club, school, state, federal) and how it can support his/her participation.

Developing strategies for accessing community resources is one step in using systems outside the family to support self-determination. Another is participating in political systems, the topic of the next module.

Supplemental Information

Networking

What is networking? How can networking benefit me and my family? What does networking require of me? These are some questions that individuals and families commonly have about networking. Before looking at how you can go about networking, let's define it.

Networking is "...the process of developing and using your contacts for information, advice, and moral support.... It's asking for help when you need it--knowing when you need it, knowing whom and how to ask for it. It's giving help, too, serving as a resource...." (Welch, 1980; p. 15). Networking is an active process requiring an individual to take the initiative. This may involve introducing yourself to influential people when the opportunity arises or telephoning for information after making a contact. Networking involves participation. If you go to a meeting, stay and mingle after the business portion is completed. Introduce yourself to the speaker or the officers of the organization. Ask questions. Volunteer to assist with a project.

Networking involves using people, "but in good networking the people you use will also be using you. The exchange may not always be immediate with instant mutual payoff, but it will all come out even in end." (Welch, 1980; p. 32). For example, a family has a teenage daughter with Down syndrome. Her next IEP meeting will involve planning for her transition. This family could network in several ways. For instance, they could attend meetings of the local Down Syndrome Association in order to meet other parents of children with Down syndrome. These parents could provide advice and support on getting the family's ideas included in the IEP. The Down Syndrome Association itself is a source of information. Another option would be to ask their daughter's teacher if he/she would be willing to ask a parent of a current or former student with Down syndrome if they would be willing to talk with them about their experiences of having a child with Down syndrome. The family could also contact the nearest parent advocacy/resource center for information about transition issues and/or assistance in preparing for the IEP meeting. These organizations can provide feedback to the family about the appropriateness of their plans for their daughter's transition. As their daughter advances through her secondary program, the family is gaining knowledge and experiences which they may be able to share with other families whose youth are just beginning high school. Members of the family can also give back by volunteering at the advocacy organizations or just listening to the concerns of other parents.

The benefits of networking are many. A sense of community develops when individuals meet with others who have similar concerns. Information is provided through tapping the knowledge and contacts of other individuals in your network. These individuals may provide referrals, knowing whom to call when a particular problem arises. Individuals in your network can give you feedback on your concerns. They provide a reality check on your perceptions of an individual or program.

Networking does take time. It takes time to attend the meetings and socialize afterwards. It takes time to do volunteer work. However, the time commitment pays off when one parent gives another the name of a doctor who works with persons with Down syndrome. It pays off when there is a concern about school programming, and the concerned parent can call a teacher he/she knows through work on a school fundraising project and have a satisfactory outcome because of that personal connection. It takes time to listen to the concerns of another parent, but their appreciation for being there for them is worth it when you need someone to listen to your concerns.

Reference: Welch, M.S. (1980). *Networking: The Great New Way for Women to Get Ahead.* New York: Harcourt Brace Jovanovich, Inc.

Family Networking Form

Dear Family Members:

As part of this training program, we would like to assist families in making connections with each other to support self-determination. If you would like to make connections with other families for the purpose of sharing information, networks, and resources that may support your self-determination or theirs, complete this form. We will then copy and distribute the information to other families who are completing this training program.

Please fill in the following for each of your adult family members who would like to participate:

Name	Address	Phone (day/eve)

For the children in the family, please complete the following:

Name	Year of Birth

Please check the areas in which you'd like to exchange information, and describe the information, support, or networks you would be willing to share with others:

___ Health Care:

___ Funding Sources:

___ Education:

___ County Case Management:

___ Employment:

___ Community Resources:

___ Other:

Materials in the *Systems Information Packet*

- Amado, A.N., Conklin, F., & Wells, J. (1990). *Friends: A manual for connecting persons with disabilities and community members.* St. Paul, MN: Human Services Research and Development Center.
- *Americans with Disabilities Act.* (Handout, no citation).
- Arc Minnesota . *Case management: Rule 185.* Minneapolis, MN: Author.
- CAPP Project Midwest Regional Office. (1990). *Collaboration among parents and health professionals (CAPP) project: Resource list.* Minneapolis, MN: PACER Center.
- Erickson, R., Johnson, D. R., & Nechville, T. (1989). Feature issue on supported employment. *Impact: Feature Issue on Supported Employment.* 2(1). Minneapolis, MN: Institute on Community Integration, University of Minnesota.
- Lindgren, J. (1991). *Moving toward independence in health care management: Outline of recommendations by a parent of adolescents with disabilities.* Minneapolis, MN: PACER Center.
- Lippert, T. (1987). *The case management team: Building community connections* (Publication No. 421-88-011). St. Paul, MN: Metropolitan Council.
- *Medical Assistance Administrative Account.* (Handout, no citation).
- Minnesota Department of Education. (1987). *Minnesota transition planning guide: Interagency office of transition services.* Minneapolis, MN: PACER Center.
- Minnesota Department of Education Office of Transition. (n.d.). *Transition resource list.* Minneapolis, MN: PACER Center.
- Minnesota Governor's Planning Council on Developmental Disabilities. (1992). *State of Minnesota Three-Year Plan.* St. Paul, MN: Author.
- Minnesota Governor's Planning Council on Developmental Disabilities. (1992). *Test your school's IQ: Integration quotient.* St. Paul, MN: Author.
- Minnesota Inclusive Education Technical Assistance Project. (n.d.). *Collaborative teamwork checklist.* Minneapolis, MN: Institute on Community Integration, University of Minnesota.
- Minnesota Integrated Education Technical Assistance Project. (n.d.). *Integrated school communities for students with developmental disabilities: Ten reasons why.* Minneapolis, MN: Institute on Community Integration, University of Minnesota.

- Minnesota Integrated Education Technical Assistance Project. (n.d.). *Integration checklist: A guide to full inclusion of students with disabilities.* Minneapolis, MN: Institute on Community Integration, University of Minnesota.
- National Transition Network. (Winter, 1993). *Parent brief: Transition requirements of the Individuals with Disabilities Education Act.* Minneapolis, MN: Institute on Community Integration, University of Minnesota.
- PACER Center. (1986). *Educational rights training after high school: Section 504 of the Rehabilitation Act of 1973.* Minneapolis, MN: Author.
- Pfaffinger, K. M., & Nelson, R. P. (n.d.). Obtaining health care. In K. M. Pfaffinger & R. P. Nelson *Quality health care for people with developmental disabilities: A guide for parents and other caregivers.* Minneapolis, MN: Institute on Community Integration, University of Minnesota.
- Tommet, P. (1992). *Minnesota support services for persons with developmental disabilities and their families.* Minneapolis, MN: Institute on Community Integration, University of Minnesota.
- Wallace, T., Thompson, S., & Johnson, D. R. (1992). *IMPACT: Feature issue on transition.* 5(3). Minneapolis, MN: Institute on Community Integration, University of Minnesota.

Organization List

- Arc Minnesota
  3225 Lyndale Ave. S., Minneapolis, MN 55408
  (612) 827-5641
- Minnesota Governor's Planning Council on Developmental Disabilities
  300 Centennial Office Building, 658 Cedar St.,
  St. Paul, MN 55155
  (612) 296-4018
- PACER Center, Inc.
  4826 Chicago Ave. S., Minneapolis, MN 55417
  (612) 827-2966
- Publications Office
  Institute on Community Integration, University of Minnesota
  109 Pattee Hall, 150 Pillsbury Drive SE,
  Minneapolis, MN 55455
  (612) 624-4512

14 Participating in Political Systems

Introduction

One of the most important resources for the exercise of self-determination is the political system of the nation. Citizens can have an impact at the local level on government bodies such as school boards, which administer federal, state, and district policies concerning the education of students with disabilities. At the county level people can impact county human services departments, which provide access to state and federal programs such as medical assistance and services for persons with disabilities. At the state and federal levels citizens can impact legislatures and the Congress, which make laws affecting all areas of life. Outcomes of efforts by persons with disabilities and their families, along with professionals and advocacy organizations, can be powerful, as demonstrated by passage of the Individuals with Disabilities Education Act and the Americans with Disabilities Act.

For persons with disabilities and their families, knowledge of and access to the political system is critical to ensuring the passage and implementation of laws and policies that support their efforts to meet their needs and have control over their lives. One way to facilitate making political systems work for individuals and families on the local level is by networking with the power brokers in a community. By getting to know these people who influence services, policies, and resource allocations that directly impact individuals with disabilities, families can have access to those who have the authority, responsibility, and/or power to generate desired change.

Another way to influence political systems is by voting. Voting is the most basic way to get involved in shaping laws and policies. It is something almost any adult - including adults with disabilities - has the right to do. To facilitate the exercise of that right, accommodations are available for persons with disabilities.

Overview of the Module

This module explores the role the political system plays in individual lives and the role individuals play in the political system. The activities look at who has the power in a community, how political systems can be used to support self-determination, and how the family member with the disability can participate in the political process by voting. The module is designed to be completed in one session of approximately two hours.

Module Goals

- *The family will gain a broader understanding of how political systems can support self-determination, and will take steps to obtain support for its self-determination through political systems.*

Module Objectives

- *The family will identify the power brokers in its community and ways to link with the power brokers and their resources to enhance self-determination.*
- *Family members will identify ways in which the political system can support its self-determination.*
- *Family members will participate in a political or policy-making meeting.*
- *The youth/young adult with a disability and other family members will identify ways that the young person can participate in a political system at any level by voting.*

Module Activities

- *Identifying Power Brokers*
- *Using the Political System*
- *Participating in Policy-making*
- *Facilitating Voting*

Activity Plans

Activity 1: Identifying Power Brokers

Introduction

In every community there are people and organizations that can assist others in meeting their needs and exploring their options. By identifying who they are and how to utilize them, one can expand opportunities for self-determination. Through this activity the family will identify power brokers in its community, the resources power brokers hold or have access to, and the means by which the family can create linkages to the power brokers and their resources in order to enhance its own self-determination.

Materials Needed

Paper, pen, flipchart; the handout, *Power Analysis: An Overview* (see pages 156-57 in the Supplemental Information at the end of this module).

Preparation for Facilitator

At the end of the previous module, discuss this activity with the family so it can start to gather the information on power brokers in its community. Hand out *Power Analysis: An Overview* (see pages 156-57 in the Supplemental Information at the end of this module).

Preparation for Family

Read the handout, *Power Analysis: An Overview* (see pages 156-57 in the Supplemental Information section of this module). The family will identify power brokers in its community, the resources the power brokers have or have access to, and how the family can create linkages to the power brokers and their resources in order to enhance self-determination. The family will have much of this information available from its own personal experiences. If it wishes to build on this information it could go to back issues of newspapers and newsletters or talk to people in the community. If family members obtain printed information about the power brokers they may like to bring it to the training session.

This module explores the role the political system plays in individual lives and the role individuals play in the political system.

Instructional Procedure

- Introduce this module and activity by describing the importance of having access to political systems and power brokers (use the information in the Introduction to this module on page 149 as the basis of your comments). Explain that in this activity the family will identify who holds power over resources it needs or desires on a local level.

- Review the handout *Power Analysis: An Overview* (see pages 156-57 in the Supplemental Information section of this module). Discuss who the family sees as power brokers within its community, which resources the family currently uses, and which resources the family could benefit from using.
- After identifying potentially useful resources discuss how the family might access or establish linkages to these resources. The following questions may be used to stimulate discussion:

1) Who are the power brokers in you community? How do you know they are the power brokers in your community?

2) Do you think they are power brokers in other communities? If yes, why? If no, why?

3) What power/resources do they have or have access to in your community?

4) When looking back at the areas in your life where you would benefit from supports/resources in order to enhance your self-determination, which of the power brokers hold or have access to the supports/resources you identified?

5) How can you create linkages to the power brokers and their resources? Do you belong to the same clubs or groups, have like interests, contribute to the same organizations or political parties, have friends or relatives in common?

Review and Reflect

Discuss what plans, if any, family members may be developing to make linkages with a power broker. What will be their first step? Who will do what and when will they do it? How will making the contact affect the family as a whole?

Activity 2: Using the Political System

Introduction

The political system of communities, counties, states, and the nation is a major power broker in our society. This activity is aimed at determining when and how the political system affects the life of the family. Through this activity the family will gain a broader understanding of how political systems can support the self-determination of the youth/young adult with a disability and other family members.

To many people, there seems to be little connection between political systems and their daily lives. If the family feels that way, it may be helpful to ask them to identify decision-making bodies, such as school boards or city councils, that do impact them in ways they feel are significant.

Materials Needed

Paper, pen, flipchart, the handout, *Political Systems* (see page 157-59 in the Supplemental Information at the end of this module).

Preparation for Facilitator

At the end of the previous module, copy and distribute the handout, *Political Systems* (see pages 157-59 in the Supplemental Information section at the end of this module). Read the handout prior to the session.

Preparation for Family

Read the handout, *Political Systems* (see pages 157-59 in the Supplemental Information section at the end of this module).

Instructional Procedure

- Introduce this activity by explaining that political systems are major power brokers at the local, state, and national levels. In this activity the family will focus on ways that citizens can influence and participate in those systems.

- Review the handout, *Political Systems* (see pages 157-59 in the Supplemental Information section at the end of this module). Discuss how the political system can support family member's self- determination. Identify areas where they could possibly benefit from support in the future and identify supports or resources that could be used to enhance their self-determination. The following questions may be used to stimulate discussion:

  1) Describe what a political system means to you.

  2) In what area(s) of your life would you as an individual family member now benefit from a political system supporting your self-determination? Please be as specific as possible. What about in the future?

  3) In what area(s) would the family unit now benefit or possibly benefit from a political system supporting its self-determination? Please be as specific as possible. What about in the future?

  4) How will the support look or be delivered? How would you receive the support or like to receive the support? Please be as specific as possible.

  5) What steps will you follow in having a political system support your self-determination?

  6) If there were particular areas in your life where you identified benefits from a political system supporting your self-determination, and you were not sure what steps to follow, how would you go about obtaining this information?

Through exercising self-determination, youth/young adults with disabilities can improve not only their own lives, but also the world in which they live.

Review and Reflect

- What effect will receiving that support have on your family's life?

Activity 3: Participating in Policymaking

Introduction

Personal advocacy within political systems doesn't always occur in a one-on-one situation. Sometimes we can accomplish more by joining a group of people who have an agenda similar to ours. In this activity, the family or an individual family member will participate in a political meeting, coalition, task force, etc. (at any level) to promote and share ideas and agendas.

Materials Needed

The handout, *Power Analysis* (see pages 156-57 in the Supplemental Information section at the end of this module); flipchart, markers.

Preparation for Facilitator

At the end of the previous module, copy and distribute the handout, *Power Analysis* (see pages 156-57 in the Supplemental Information section at the end of this module). Read *Power Analysis.* Assist the family with identification of organizations that are working on issues of interest to the family or individual family member.

Preparation for Family

Read *Power Analysis* (see pages 156-57 in the Supplemental Information section at the end of this module). Identify organizations that are working on issues of interest to the family or an individual family member.

Instructional Procedure

- Ask the family to identify organizations that are affecting policies or programs important to family members. List on flipchart.
- Ask each family member to identify a meeting or group in which he/she may want to participate. Identify the information and preparation that would be needed for the person to attend. List on the flipchart.
- Ask if any family members are willing to commit to attending the meetings they identified. If so, list the steps that need to be completed to follow through with the activity. Guide the family in problem-solving related to any of the steps.

Review and Reflect

- How can participation in this type of activity help in obtaining more control in your own life (world)?

Many people have never thought about individuals with disabilities becoming involved in policymaking. This may be a new and challenging idea for the young person with a disability and his/her family. It may be helpful for them to know that many people with disabilities, known as **self-advocates,** ***are sitting on advisory committees of organizations across the country and are also organizing the national self-advocacy movement.***

Activity 4: Facilitating Voting

Introduction

The political system is something upon which we can have an impact. Through this activity the family will gain a broader understanding of the means by which the youth/young adult with a disability can have an impact on political systems. The family will develop a plan for supporting the young person in voting at any level in a political system, including local, school, state, national, club or organization elections.

Materials Needed

The handout, *Political Systems* (see pages 157-59 in the Supplemental Information section at the end of this module); flipchart and markers.

Preparation for Facilitator

At the end of the previous module, copy and distribute the handout, *Political Systems* (see pages 157-59 in the Supplemental Information section at the end of this module). Read the handout prior to this session.

Preparation for Family

Read the handout, *Political Systems* (see pages 157-59 in the Supplemental Information section at the end of this module). Identify possible voting opportunities for the youth/young adult with a disability and means to support his/her participation in the voting opportunity.

Instructional Procedure

- Introduce this activity by explaining that there are opportunities for the youth/young adult with a disability to influence political systems by voting. In this activity, the family will identify some of those opportunities and the steps that need to be taken to support voting by the young person.
- Discuss opportunities the youth/young adult with a disability has had and will have to participate in the voting process. Use the following questions to stimulate discussion:

  1) What election(s) could the young person participate in the voting process?

  2) What steps would need to be taken to support the young person's participation in the voting process?

  3) What accommodations would be needed, and who will be involved in providing accommodations and support?

This curriculum started out focusing on exercising self-determination in daily life through making choices, solving problems, and pursuing goals. At this point, the definition has expanded to include having an impact on a much larger scale, such as an organization, community, state or nation.

Review and Reflect

- How does voting enhance self-determination?

Preparation for Next Module

- Copy and distribute the *Family Education Curriculum Modules List* (see pages 46-47 in the Supplemental Information at the end of Module 3). Ask the family members to review the list and reflect on the following: What do they do well to support self-determination and in what areas do they need to improve their support of family members's self-determination?
- Bring to the next session a copy for each participant of the future map developed by the focus person in Module 2, as well as all the charts made throughout the curriculum.
- Bring to the next session the flipcharts made throughout the curriculum.

In this module, family members have moved from exercising self-determination solely for their own or other family member's benefit to exercising it for the added benefit of others outside the family whose lives would be improved by policies and laws.

Supplemental Information

Power Analysis: An Overview

Understanding who has the power and influence in a community is critical to getting needs met by systems and using systems to support self-determination. To identify who has power over what resources in your community, think about the following social and political systems, what they have to offer you, and who controls them:

- city government
- corporations
- civic groups
- banks
- the Chamber of Commerce
- school boards
- ministerial alliances
- city councils/county commissions
- nonprofit associations
- neighborhood coalitions/groups
- media associations
- unions
- arts councils
- churches
- youth organizations
- athletic programs

In looking at the above list, think about the following:

- Who are the individuals making the decisions for/with the group?
- Are certain individuals tied to several of the groups?
- Do the groups have interlocking boards of directors with banks, businesses, other organizations?
- Are there people who contribute heavily to political campaigns?
- Are certain persons given a lot of media coverage?

An informal system of influence also exists in every community. This system is harder to identify in urban areas than in rural areas. In rural areas, attention should be paid to:

- Who drinks coffee at the local cafe each morning?
- Who spends time at the Elks, Jaycees, etc.?
- Who attends most of the civic group meetings?
- Who has been on the school board for more than three terms?
- Who raises the most money for political candidates?

It is frequently true that the private sector (business) usually leads and the public sector (government) follows. If you want to determine who are the power brokers in a community, read the business pages of your newspapers. This will help you determine who has the real power; these people will often work behind the scenes to move city, county and state governmental decisions.

Once your analysis is complete, you will have an accurate picture of which individuals and groups heavily influence community decision making. This knowledge enables your family to develop sound and practical strategies for influencing decisions and policies within your community.

Adapted with permission from Male, R. & Lopp, D. (no date). *Power analysis: An overview*. Denver: Community Resource Center.

Political Systems

- **Candidate**: A person who seeks or is nominated for an office, honor, etc.
- **Governing**: To exercise the function of government.
- **Platform**: A set of principles on which a political party takes a public stand.
- **Politics**: The science or art of government, the practice or profession of conducting governmental affairs.
- **Vote:** A formal expression of opinion or choice made by an individual or body of individuals.
- **Voting**: To express an opinion or choice by casting a ballot.

The Random House Dictionary: Concise Edition

Political systems include the government and other organizations, such as political parties, that are involved in governing or electing people to govern. In a democracy such as the United States, citizens are able to express their opinions about what government should do and who govern. At the most basic level, individuals who are 18 years and old (with a few exceptions) are able to vote. By voting, people decide who should be in their government and what the policies of the government should be. Individuals may also decide to get involved in political systems by supporting a particular candidate for office or volunteering to do work for a political party. Or they can run for office themselves.

Registering to Vote

Before you can vote, you must register to vote. Throughout the U.S., states and counties have different processes to register to vote. They also may have different requirements on who may vote, such as how long you must live in an area (residency) before you can vote there and how far in advance you have to register to vote before election day in order to be able to vote in that election. To get information on how to register to vote, call the county courthouse or the League of Women Voters in your area.

Supporting Candidates

People can also get involved in government by supporting a candidate for an office or campaigning for a particular issue. Every candidate needs help and you don't have to be eligible to vote in order to work in a campaign. People who work in a campaign do such things as pass out leaflets and buttons, call people to talk to them about their candidate or encourage them to vote, drive people to the polls, and attend political rallies.

Running for Office

The highest level of involvement is running for office. People who run for office often start at the local level by being involved in city or county government or with a political party at a local level. As they become more well known, they may decide to run for office at the state level, either for the state legislature or an executive office such as governor. If they want to influence what the government does at the national level, they may run for Congress or President.

If politicians want to stay in office, they need to know if what they are doing is what the people who vote want done. If the voters don't like what politicians are doing, the politicians can either change what they are doing or convince the voters what they are doing is right. Voters have the final say because if they do not like what someone is doing, they can vote for someone else in the next election. If enough people do not like what a politician is doing, s/he will not be reelected.

Conclusion

Political issues determine what goes on in people's daily lives. These issues are decided by the people who get elected. People often think that they can't do anything to change the American system of politics. However, the system is only made up of people. "All it takes is for all of us to remember that politics is the way people get into and keep the jobs that affect our lives. If we don't keep an eye on things and help to elect people who will do things the way we want them to be done, then we deserve to be disappointed." (Samuels, 1988, p. 114).

Reference: Samuels, C. K. (1988). *It's a free country! A young person's guide to politics and elections*. New York: Atheneum.

Additional Readings

- Fradin, D. B. (1985) *Voting and Elections*. Chicago: Children's Press.
- Modl, T. (Ed.) (1988). *America's elections: Opposing viewpoints*. St. Paul, MN: Greenhaven Press.
- O'Donnell, J. J. (1978). *Every vote counts: A teen-age guide to the electoral process*. New York: Julian Messner.
- Samuels, C. K. (1988). *It's a free country! A young person's guide to politics and elections*. New York: Atheneum.

15 Continuing the Journey

Introduction

Over the course of the last several months, the family with whom you have been working has taken part in an educational program designed to enhance its ability to support the developing self-determination of the youth/young adult with a disability and other family members. Through participation in the program, family members have increased their awareness of the importance of self-determination in daily life and enhanced their understanding of the skills, knowledge, and attitudes necessary for the responsible exercise of personal control. Participants have supported the young person through creating a vision for his/her future that maximizes the personal control the individual can exercise. Parents, siblings, and the individual with a disability have also learned concrete strategies that can be employed to make that vision a reality.

The perspectives and skills that family members have learned through this program should be considered as a starting point. They are necessary, but not sufficient to enhance the self-determination across the life-span. Unless members of the family demonstrate a continued commitment to work collaboratively in support of each other and to balance self-determination with the needs of the group, the changes that have taken place will be short-lived.

It should not be assumed that all members of the family have learned everything they need to know about self-determination or that their support skills in this area are fully developed. For most families, it is likely that some areas were encountered in which learning came quickly and was easy. It is also probable, however, that each family faced some challenges. These are likely to have occurred in areas in which the family's style of functioning was well ingrained and more difficult to change. In areas such as these, continual reflection and practice will be required if family members are to maintain the gains they have made.

Overview of the Module

This module provides closure to the education and support curriculum and encourages families to continue to work toward the enhancement of the self-determination of all members. The emphasis is therefore placed on the idea that this is the beginning of a long journey rather than the end, and that family members will need to support each others' continual growth in this area. The module is designed to be completed in one session of approximately two hours.

Module Goals

- *Family members will review what they have learned from their participation in this curriculum.*
- *The family will develop an action plan to work on areas of self-determination that require continued practice.*

Module Objectives

- *Family members will review what they have learned from participating in this curriculum.*
- *The family will review the future map of the youth/young adult with a disability, and update it, if necessary.*
- *The family will conduct a "self-assessment" of the degree to which it is currently able to support the self-determination of family members and will prioritize areas that need improvement.*
- *Family members will develop action plans that will provide direction for further growth and learning within each need area identified.*

Module Activities

- *Review and Reflection*
- *The Personal Futures Plan: A Second Look*
- *Developing Action Plans to Enhance Self-Determination*

Activity Plans

Activity 1: Review and Reflection

Introduction

In this activity, you will guide family members through a review of the modules in which they have participated, asking them to identify what they learned through taking part in each module.

Materials Needed

Paper, pen, or a flipchart and markers; copies of the *Family Education Curriculum Modules List* (see pages 46-47 in the Supplemental Information section of Module 3) to be handed out at the end of the previous module; all charts made in previous modules.

Preparation for Facilitator

Review notes, charts, handouts and other materials from the modules that the family has completed; copy the *Family Education Curriculum Modules List* (see pages 46-47 in the Supplemental Information section of Module 3) and distribute copies at the end of the previous module; collect and bring all charts made in previous modules.

Preparation for Family

Prior to this session, the family will review the *Family Education Curriculum Modules List* (see pages 46-47 in the Supplemental Information section of Module 3) and reflect upon the modules in which they have participated. They should think about what they and their family do well to support self-determination and identify those areas which they and their family need to improve if the self-determination of family members is to be enhanced in the future.

Instructional Procedure

This module provides closure to the education and support curriculum and encourages the family to continue to work toward the enhancement of the self-determination of all its members.

- Introduce this module and activity by explaining that the module is a review and summary of all they've learned through participating in this curriculum

- Referring to the *Family Education Curriculum Modules List*, begin by asking each family member to discuss at least one thing he/she has learned from participating in each of the modules. Begin with the earliest modules and progress to those that have most recently been completed. List their responses on the flipchart. You may want to refresh their memories by looking at flipchart sheets from specific modules. Questions for discussion include:

  1) How has your individual self-determination changed through participating in these modules?

2) What skills or information have you learned that can be used to support the self-determination of yourself or others?

- Ask each family member to name at least one thing that the family does well to support the self-determination of all family members (i.e., what are their strengths as a family?). List responses on flipchart.
- Ask the family to identify those areas that they need to continue to work on in the future if they are to support the self-determination of all its members. List responses on the flipchart.

Activity 2: The Personal Futures Plan: A Second Look

Introduction

The primary goal of the curriculum has been to enhance and support the self-determination of the youth/young adult with a disability. In Module 2, a Personal Futures Plan to enhance the self-determination of the family member with a disability was developed. As much as possible, activities in subsequent modules built upon this plan. The purpose of this activity is to review the future map developed in Module 2 and assess the progress the family has been made toward attainment of its goals.

Materials Needed

Future map developed in Module 2 and other materials from subsequent modules that built upon this plan, (e.g., Activity 2 of Module 6). Paper and pen, or a flipchart and markers.

Preparation for Facilitator

Review future map and subsequent materials based upon it.

Preparation for Family

None.

Instructional Procedure

- Introduce this activity by explaining that the primary goal of the curriculum has been to enhance and support the self-determination of the youth/young adult with a disability. The focus has been primarily on developing the skills and support to reach goals identified in the future map (Module 2).
- Review the future map developed by the focus person in Module 2, concentrating on the goals that were developed as part of the plan.

The primary goal of the curriculum has been to enhance and support the self-determination of the youth/young adult with a disability.

After the initial plan has been reviewed, encourage family members to assess the impact on the family of activities in subsequent modules that were based on the plan.

- Discuss with family members how implementation of the Personal Futures Plan has progressed. Encourage the family to assess each goal on the future map and make a determination as to the extent to which it has been achieved. Ask family members to consider the extent to which: (1) goals from the original future map are no longer a priority, (2) new goals need to be added to the map, and (3) new strategies need to be developed to assist the family in achieving goals specified in the original future map.

Activity 3: Developing Action Plans to Enhance Self-Determination

Introduction

In this activity, the family will develop a plan to continue to work on those areas targeted for further change/improvement as identified in Activity 2.

Materials Needed

Paper and pen, or a flipchart and markers; list of areas that the family feels they need to work on from Activity 2; future map and any changes in the map made in Activity 2.

Preparation for Facilitator

None.

Preparation for Family

None.

Instructional Procedure

- Introduce this activity by explaining that the family will develop a plan to continue work on areas targeted for further change/improvement in Activity 2.
- Post the list from Activity 2. Have the family work collaboratively to prioritize up to three of the areas for needed change/improvement that they identified.
- Working on one area at a time, facilitate family brainstorming of ways that it can work on each priority area. Make sure that during this part of the activity, family members concentrate solely on generating strategies for change within each area rather than attempting to evaluate them.

Often, changes in how people think and act do not happen quickly. As the family lays out its commitment to support self-determination through an action plan, it may be important to point out that it will take time to implement that plan and that there will be setbacks.

- Based upon the ideas that have been generated from the family brainstorming session, assist the family in evaluating each proposal focusing on the extent to which the plan is realistic, likely to stimulate change, apt to be motivating enough for the family to carry it out, fits into the family's schedule, and involves all family members.

- Working on one area at a time, assist family members in developing action plans to stimulate change in target areas. Each action plan should include:

  1) Short- and long-term goals for each area.

  2) A plan detailing what is going to be done to attain each goal.

  3) Identification of which family members are responsible for carrying out the plan.

  4) The specific tasks for which each family member will be responsible.

  5) A plan to evaluate how successful the family has been in attaining its goal(s).

  6) A date at which time the family agrees to review progress toward the goal.

- Discuss with family members how their action plans fit in with the goals identified in the future map, using the following questions:

  1) Are the areas in which work needs to be accomplished similar to those identified in the initial future map?

  2) To what extent will the action plan just developed enhance the self-determination of the youth/young adult with a disability?

  3) If the goals are dissimilar, do the future map or the action plan need to be changed?

Conclusion

End this final session by thanking the family members for their cooperation. Share what you as an individual have learned while working with the family and how this has affected your self-determination. Share what you see as the strengths of the family.

As the curriculum ends, encourage the individual and family to continue practicing the skills they've learned here, and most of all continue talking to one another about what they want and need as support for self-determination.